

MONITORING AND BLUNTING AND THE EXPERIENCE OF ADJUVANT
CHEMOTHERAPY FOR EARLY BREAST CANCER

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DECLARATION

I declare that this thesis reports my original work, that no part has been previously accepted and presented for the award of any degree or diploma from any university and that, to the best of my knowledge, no material previously published or written by any other person is included, except where due acknowledgement is given.

A handwritten signature in black ink, consisting of a series of loops and a long horizontal stroke, representing the name Sarah Catherine Davenport.

Sarah Catherine Davenport

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ABSTRACT

Breast cancer is the greatest health care challenge facing Australian women. While the prognosis for women diagnosed with early breast cancer (EBC) is excellent, many will experience significant deleterious effects on physical and psychological wellbeing during and following treatment to eradicate the disease. Of particular concern is adjuvant chemotherapy treatment. Patients report great variations in physical side effects and psychological distress during and following chemotherapy treatment, the reasons for which are little understood. Past research suggests that the variations may be accounted for by monitoring and blunting coping styles. Monitoring refers to the persistent efforts to seek out information about the stressful situation while blunting refers to the efforts to avoid or escape from information about the situation. Monitoring coping has been implicated in decreased physical and psychological wellbeing via increases in intrusive and avoidant ideation, greater chance and powerful others locus of control beliefs and higher risk perception of cancer recurrence. Conversely, blunting coping has been implicated in increased physical and psychological wellbeing, greater internal locus of control beliefs and lower risk perception of cancer recurrence.

The present study involved fifty-three women diagnosed with EBC who completed questionnaires at five time-points: prior to chemotherapy treatment, after the first, middle and final treatments, and six month following treatment completion. Monitoring and blunting coping styles were assessed at prior to chemotherapy, perceived risk of recurrence at six month follow-up, and levels of side effects, anxiety and depression, intrusive and avoidant ideation and health locus of control beliefs at each time-point. Analyses accounted for demographic, health, disease and treatment characteristics as well as bone marrow, hepatic and renal functioning. The results showed that the use of blunting coping directly increased anxiety levels while the use of both monitoring and blunting coping directly increased side effects. The use of blunting coping and the use of both monitoring and blunting coping indirectly increased anxiety and side effects, via intrusive and avoidant ideation. In contrast, the use of blunting coping and the use of both monitoring and blunting coping indirectly increased and decreased depression, via intrusive and avoidant ideation. It was also found that monitoring coping was associated with greater internal, chance and powerful others locus of control beliefs while blunting coping was associated with greater chance locus of control beliefs. Participants using

both monitoring and blunting coping reported more chance locus of control beliefs. Lastly, it was found that blunting coping was associated with lower levels of personal perceived risk of recurrence.

These results indicate that monitoring and blunting coping styles significantly affect patients' psychological and physical wellbeing, locus of control beliefs and risk perception of recurrence during and following chemotherapy treatment. Theoretically, the study emphasises the need to accurately and appropriately conceptualise and measure monitoring and blunting coping. Clinically, the study highlights the need to identify patients at risk of poor wellbeing during and following treatment due to their chosen coping style. The possibility of tailoring medical care to patients' coping styles and implementing psychological interventions to alter coping styles are discussed.

CHAPTER ONE

Breast Cancer in Australia

Cancer is one of the major health challenges facing Australians. It is the second major cause of death for Australians, after cardiovascular disease (Australian Institute of Health and Welfare & Australasian Association of Cancer Registries: AIHW & AACR, 2004). To understand the significant burden cancer presents for the health care system and the community, the following chapter will outline the current and projected incidence and mortality rates of cancer in Australia and the broad factors affecting these rates. There will be a special focus on the rates of breast cancer as a disease of particular concern to many Australian women.

1.1 Definition of Cancer

Cancer is a term that can be used generally to describe a diverse set of diseases. Usually, the cells that make up the human body grow and multiply in a controlled and orderly manner. However, after being affected by a carcinogen or developing a random genetic mutation, cells sometimes grow and multiply in an uncontrolled manner. These abnormal cells form a mass called a tumour or neoplasm. Tumours can be benign or malignant. Benign tumours are innocuous and grow slowly. They do not invade other tissues or spread to other parts of the body. They can, however, grow to interfere with the body's existing structures. This interference can cause serious complications and in some cases even death. In 2001, there were 126 registered deaths from benign tumours (AIHW & AACR, 2004; Lenhard, Osteen, & Gansler, 2001).

Malignant tumours are cancers that can invade locally and spread to other parts of the body. Cancer cells from a malignant tumour can travel through the circulatory and lymphatic systems and establish themselves in other parts of the body. The original tumour is known as the primary tumour and the tumours that develop in other parts of the body as a result of the spreading of cells are known as secondary tumours or metastases. People who are diagnosed with primary tumours are said to have early stage cancer while those who are diagnosed with secondary tumours have advanced stage cancer. The damage caused by malignant tumours varies as a result of the pattern of growth and spread of the cancer and the surrounding cells and structures. Malignant

tumours have their own pattern of growth and spread depending on the part of the body in which it occurs. Unfortunately, knowledge of the nature, causes and optimal treatment of the different forms of cancer varies considerably (AIHW & AACR, 2004; Lenhard et al., 2001).

1.2 Cancer Incidence

According to the Australian Institute of Health and Welfare (AIHW), there were 88,398 new cancer cases in 2001 compared with 65,966 new cases in 1991, excluding non-melanoma skin cancers. Colorectal cancer was the most common cancer in 2001 (12,844), followed by breast cancer (11,886), prostate cancer (11,191), melanoma (8,885), and lung cancer (8,275). Together these accounted for 60% of all cancers in 2001 (AIHW & AACR, 2004).

1.2.1 Cancer Incidence and Age

The risk of cancer increases with age, with four times as many cancers diagnosed in those over the age of 60 years compared with those under the age of 60. In 2001 for all cancers combined, the age-standardised incidence rates were 15.2 cases per 100,000 population for people aged less than 15 years, 95.6 for 15-44 year olds, 100.5 for 45-64 years olds, and 2,190.2 for people aged 65 years and over. In other words, of the people diagnosed with cancer, 0.7% of all cancers occur in those aged less than 15 years, 9.4% in the 15-44 years age group, 32.6% in the 45-64 year age group, and 57.2% in those aged 65 years and over. Age-standardised rates are rates that are adjusted for age to enable comparisons to be made between populations that differ in age (AIHW & AACR, 2004).

The most common cancers in each age range vary. Melanoma and breast cancer are most frequently diagnosed in people aged 15-44 years while breast, colorectal, melanoma, prostate, and lung cancers are most frequent in those over 45 years. Some cancers attain their highest rates in early or middle life and these remain constant in older age groups (for example, breast and cervical cancer) or decline (for example, testicular cancer) (AIHW & AACR, 2004).

1.2.2 Cancer Incidence and Gender

In 2001, overall incidence rates revealed that cancer was more common in males than females. The age-standardised incidence rate in 2001 for all cancers combined was 541.4 new cases per 100,000 for males and 393.3 for females. That is, it is expected that one in three men and one in four women will be diagnosed with a cancer in the first 75 years of life. The average age of the first diagnosis for males was 66 years compared with 64 years for females (AIHW & AACR, 2004).

Between 1991 and 2001, age-standardised incidence rates for all cancers combined increased for males by an average of 4.4% per annum until 1995 and then declined by an average of 1.3% per annum until 2001. Males had a higher incidence rate for every cancer site, except for breast, thyroid and anus. In males, prostate cancer was the most common cancer (11,191 new cases diagnosed in 2001), followed by colorectal cancer (6,961), lung cancer (5,384), and melanoma (5,024). These four cancers accounted for 60% of all cancers in males (AIHW & AACR, 2004).

The incidence rates for males have been strongly influenced by the rise and fall of prostate cancer incidence during this period. Rates for prostate cancer were stable until 1989. Between 1990 and 1994 there was a dramatic rise in the number of new cases registered due to the introduction of Prostate-Specific Antigen (PSA) testing in some regions of Australia. PSA testing aims to identify cancers before the onset of clinical symptoms. From 1994 to 1997 the rate fell by 30% indicating a return to the underlying rate and there has been little change since. Given the frequency of prostate cancer diagnosis, small increases in incidence can mean a substantial shift in the number of new cases (AIHW & AACR, 2004).

For females, age standardised rates increased by an average of 1.5% per annum until 1995 and remained constant until 2001. In females, breast cancer (11,791) was the most common cancer, followed by colorectal (5,883), melanoma (3,861) and lung cancer (2,891). These four cancers accounted for 60% of all cancers in females. Similar to the incidence rates for males, the rates for females have been influenced by the introduction of routine mammography screening in women at highest risk of breast cancer, that is, those over the age of 50 years. The increase indicates the detection of existing breast

cancer in women and the levelling off is a return to the underlying rate (AIHW & AACR, 2004).

1.2.3 Cancer Incidence and Residence

Incidence rates for individual state and territories are based on cancer registration in the patients' state and territory of residence at the time of diagnosis. Differences in state and territory cancer incidence rates may be explained by normal incidence rate fluctuations, variations in underlying cancer risk, the availability and utilisation of diagnostic procedures, and reporting and coding inconsistencies. To reduce the problems of statistical variation due to a small number of cases, the numbers and rates presented for the states and territories are annual averages of the five-year period of 1997-2001 (AIHW & AACR, 2004).

South Australia (SA) reported the highest incidence rates for males (509.3 cases per 100,000 population), followed by Victoria (Vic: 500.5), Queensland (Qld: 498.2), the Australian Capital Territory (ACT: 496.0), Tasmania (Tas: 480.8), New South Wales (NSW: 482.0), Western Australia (WA: 456.0), and the Northern Territory (NT: 452.4). For females, the ACT reported the highest rate (382.1 cases per 100,000 population), followed by NSW (381.6), Qld (365.6), Vic (359.1), SA (358.2), Tas (354.3), the NT (330.2), and WA (330.2) (AIHW & AACR, 2004).

1.2.4 Projected Cancer Incidence

The cancer incidence rates are projected to remain fairly stable on the whole, with an increase of 2% in age-standardised incidence rates for females from 393.3 per 100,000 in 2001 to 402.9 per 100,000 in 2011 and a decrease of 1% for males from 541.4 per 100,000 in 2001 to 538.3 per 100,000 in 2011. When considering the overall incidence rates, it is expected that there will be a considerable increase in the numbers of new cases diagnosed. The expected increase in incidence is due to the projected increase in the Australian population in the older age groups where the incidence rates of cancer are highest (AIHW, 2005).

Current estimates indicate that the total population is expected to increase by 12% from 19,413,240 in 2001 to 21,765,911 in 2011 but the increase in the age group 65 and over is expected to increase by 30% from 2,435,534 to 3,169,188. Indeed, evidence of this

already exists with the increase in cancer incidence in the past ten years far greater than the growth of population during this time, roughly 36% compared to 12%. This means that the number of Australians diagnosed and living with cancer will continue to rise in the coming years (AIHW, 2005; AIHW & AACR, 2004; Senate Community Affairs References Committee, 2005).

The number of new cases is projected to increase by 32% for men from 47,820 in 2001 to 63,087 in 2011 and by 29% for women from 40,578 in 2001 to 52,356 in 2011. For men, the most common cancers are expected to change slightly with a projected increase in the rates of prostate cancer (24%), colorectal (15%), melanoma (11%) and lung (10%). For women, the most common cancer are expected to be the same as those in 2001, breast cancer (28% of new cases), colorectal (15%), melanoma (9%), and lung (8%) (AIHW, 2005).

1.3 Cancer Mortality

In 1991, there were 30,928 deaths due to cancer (or 26% of all deaths), which rose by 17.4% to 36,750 deaths (or 29% of all deaths) in 2001. These rates are those in which cancer was the underlying cause of death as coded on the death certificates. There were an additional 4,519 deaths where cancer was an associated cause reported on the death certificate in 2001. Among the 4,519 cases, the most common underlying causes of death were ischemic heart disease, chronic obstructive pulmonary disease and stroke (AIHW & AACR, 2004).

Person-years of life lost (PYLL) describes the number of years of life lost due to an early death from cancer, that is, before the expected age of 75 years. In 2001, there were an estimated 257,458 PYLL as a result of people dying of cancer before the age of 75. The PYLL estimates are typically dominated by the most common cancers as they represent the large number of cases diagnosed. The cancer responsible for the highest number of PYLL were lung cancer (44,978), followed by colorectal cancer (29,768) and breast cancer (28,733) (AIHW & AACR, 2004).

1.3.1 Cancer Mortality and Age

While the pattern of deaths across age groups is similar to that of incidence, a larger proportion (72.5%) of cancer deaths occurs in those aged 65 years and over. The age-

specific incidence rate for all cancers combined was 15.2 per 100,000 population for people less than 15 years, 95.6 for 15-44 year olds, 700.5 for 45-64 year olds, and 2,190.2 for those 65 years and over (AIHW & AACR, 2004).

1.3.2 Cancer Mortality and Gender

In 2001, cancer accounted for 31% of male deaths and 26% of female deaths. The cancers most commonly causing death were lung (4,657), prostate (2,718) and colorectal cancer (2,601) in males and breast (2,612), lung (2,382) and colorectal cancer (2,153) in females. Between 1991 and 2001, the age-standardised cancer mortality rate for males was 270 cases per 100,000 population until 1995 and then declined by 1.8% until 2001. For females, the rate was 160 cases per 100,000 population until 1997 and then declined by 1.4% until 2001. Declines are thought to be due to improvements in screening, accuracy of diagnosis and the introduction of increasingly effective treatments (AIHW & AACR, 2004).

1.3.3 Cancer Mortality and Residence

The 1997-2001 cancer mortality rates reported for males were highest in Tas (262.7 cases per 100,000 population), Qld (251.7), Vic (249.9), SA (247.7), WA (247.5), the NT (246.5), NSW (246.4), and lowest in the ACT (219.6). For females, the rates were highest in the NT (187.9 cases per 100,000), Tas (169.8), ACT (159.0), Vic (155.0), SA (149.5), WA (149.3), Qld (147.0), and lowest in NSW (146.7) (AIHW & AACR, 2004).

Similar to state and territory incidence rates, mortality rates refer to the state and territory of usual residence. However, it is not uncommon for people diagnosed with cancer to travel interstate for treatment and palliative care, so state of usual residence at diagnosis may differ from the state of residence at time of death. This is particularly the case for the ACT. During the period 1997-2001, 16.3% of those dying of cancer in the ACT usually resided in another state or territory, the majority (15.1%) coming from NSW (AIHW & AACR, 2004).

1.4 Cancer Survival

1.4.1 Cancer Survival and Age

Cancer survival has continued to improve in the past two decades in Australia. Relative survival rates compare the crude survival rate (the time between diagnosis and death)

and the expected survival time in the general population. The highest five-year survival proportions were reported in the 20-29 year age group at 82.9% for males and 87.2% for females. Survival proportions then declined in the later year groups to 30.2% for males and 32.7% for females in the 90-99 year group (AIHW & AACR, 2001a).

1.4.2 Cancer Survival and Gender

On average, females have higher survival rates than males. For the period 1992-1997, females had a five-year relative survival rate of 63.4% compared to 56.8% for males. There were significant improvements in one, five, and ten-year survival rates for both males and females across the periods 1982-1986 and 1992-1997. One-year survival rates increased from 64.5% to 73.6% for males and 73.5 to 77.5% for females. Five-year survival rates increased from 43.8% to 56.8% for males and 55.3% to 63.4% for females. Ten-year survival rates increased from 38.9% to 43.2% for males and 50.8% to 55.0% for females (AIHW & AACR, 2001a).

Cancer sites with the highest five-year survival rates in males were cancers of the testis (95.4%), thyroid (87.9%), and prostate cancer (82.7%). Those cancer sites with the lowest survival rates were cancers of the pancreas (5.4%), lung (11.0%), unknown primary site (13.4%), stomach (22.6%), and brain (23.8%). For women, the highest five-year survival rates were cancers of the thyroid (95.6%) and breast (84.0%). Those with the lowest survival rates were cancers of the pancreas (5.2%), unknown primary tumour (11.5%), lung (14.0%), brain (23.8%) and stomach (24.8%) (AIHW & AACR, 2001a).

1.5 International Comparisons of Cancer Incidence, Mortality and Survival

In comparison with other developed countries, Australia has comparatively high incidence but low mortality rates, suggesting that Australians experience relatively good cancer survival. This is most likely due to early detection and effective treatment. The AIHW reported the international incidence, mortality and survival rates. These rates are expressed in an age-standardised rate based on World population figures (ASR(W)) and are estimates for the year 2000. These estimates were based on the most recent data available, generally three to five years earlier. Incidence and mortality rates were available for a range of countries while survival rates were available for a selection of developed countries (AIHW & AACR, 2004).

The male World incidence rate of cancer was 201.9 cases per 100,000 population, with rates for developed countries significant higher (301.0) and for underdeveloped countries lower (153.8). When comparing a range of world regions, Australia's incidence rate for males was third (355.3) behind New Zealand (375.3) and the United States (361.4). Australia's rates were followed by Canada (323.4), Western Europe (318.7), Eastern Europe (290.0), Southern Europe (275.4), Northern Europe (263.4), the United Kingdom (260.3), and South-East Asia (131.1) (AIHW & AACR, 2004).

For females, the World incidence rate of cancer was 157.8 cases per 100,000 population. Again, the incidence rate for developed countries was higher (218.3) and for underdeveloped countries was lower (127.9). Australia's incidence rate for females was also third (279.3) compared to New Zealand (303.2) and the United States (283.2). Australia's rates were followed by Canada (266.0), Northern Europe (235.1), the United Kingdom (234.3), Western Europe (230.7), Eastern Europe (197.2), Southern Europe (194.3), and South-East Asia (120.1) (AIHW & AACR, 2004).

The male World incidence rate was 134.4 cases per 100,000 population, with a higher rate for developed countries (173.9) and a lower rate for underdeveloped countries (112.9). The mortality rate for males in Australia (150.9) was lower than almost all other regions except South-Eastern Asia (101.3). The highest mortality rates were reported in Eastern Europe (199.9), followed closely by Western Europe (185.2), Southern Europe (172.1), and the United Kingdom (171.0), Northern Europe (168.2), New Zealand (167.3), and Canada (160.5) (AIHW & AACR, 2004).

The female World incidence rate was 88.3 cases per 100,000 population. Similarly, a higher rate was reported for developed countries (103.1) and a lower rate for underdeveloped countries (77.5). The mortality rate for females in Australia was one of the lowest of the regions (103.2), ahead of South-Eastern Asia (74.1), Southern Europe (92.7), and Eastern Europe (101.4). The highest rates were reported for New Zealand (131.1), the United Kingdom (128.1) and Northern Europe (121.7), Canada (116.7), the United States (116.4), and Western Europe (110.4) (AIHW & AACR, 2004).

Consideration of the international survival rates shows that the five-year survival rate overall and for individual cancer sites in Australia is one of the best of those examined. For males, the Australian five-year survival rate was second (48%) behind the United States (58%). Australia was followed closely by Iceland (47%), Finland (38%), Europe (35%), Italy (34%), Denmark (32%), England/Wales (31%) and Scotland (29%). For females, the five-year survival rate in Australia also second (59) to the United States (61%) and followed by Iceland (56%), Finland (54%), Italy (52%), Europe (50%), Denmark (47%), England/Wales (43%) and Scotland (41%). It should be noted, however, that differences in definitions and coding as well as the presence of lead-time bias can make some direct comparisons difficult. Lead-time bias is when the period between diagnosis and death is extended due to the implementation of screening (AIHW & AACR, 2001a).

1.6. Cancer Expenditure

Undoubtedly, cancer represents a significant threat to the wellbeing of all Australians. The severity of this threat is reflected in the large amount of money spent on cancer services and research in Australia. It is estimated that in 2000-2001, cancer expenditure was \$2.7 billion, representing 5.7% of Australia's total health expenditure. The majority of the expenditure was in hospital care (\$1,988m), followed by out-of-hospital medical expenses (\$343m) and pharmaceuticals (\$183m). Total expenditure on cancer services was 9% of total hospital expenditure. Cancer research was funded at a cost of \$215m in 2000-2001, representing 18% of all health research expenditure in Australia (AIHW & AACR, 2004).

The average cancer expenditure per person has been estimated at \$146 for males and \$135 for females in 2000-2001, although estimates were higher in older age groups. In the 65-74 year age group, average expenditure per person in 2000-2001 was \$641 for males and \$389 for females, while in the 75 years and over groups, the averages were \$984 for males and \$480 for females. The considerable cost of cancer services and research in Australia has risen by 31% from 1993-1994 to 2000-2001 and is expected to continue growing in the future (AIHW & AACR, 2004).

1.7. Breast Cancer

1.7.1 Breast Cancer Incidence

For Australian women, the risk of breast cancer is of great concern. Breast cancer is the most frequently diagnosed and fatal cancer in women. As such, it affects many women and their families and friends in Australia every year. In 2001, there were 11,791 women diagnosed with breast cancer (or 117.2 cases per 100,000 population). This represents 29.1% of all cancers diagnosed in women. This is up from 7,992 (100.4 cases per 100,000) in 1991, with an average increase of 1.4% per annum between 1991 and 2001. As outlined, there was an inflection in the incidence rate around the implementation of routine screening program called BreastScreen Australia in 1995, indicating the detection of previously undiagnosed cases. In other words, around one in 11 Australian women will develop breast cancer in their lifetime (Australian Institute of Health and Welfare & National Breast Cancer Centre: AIHW & NBCC, 2006).

Although figures are not currently available, the number of women diagnosed with early (EBC), as opposed to advanced or late stage (ABC) breast cancer, is increasing (AIHW & AACR, 2004). This is undoubtedly due to the increased awareness of breast cancer and the improvements and access to screening across Australia.

In 2001, there were no cases of breast cancer in females under 15 years, 123.1 cases per 100,000 population for 15-44 year olds, 352.7 for 44-65 year olds, and 304.9 for 65 year olds and over. The ACT reported the highest incidence rates for breast cancer (122.1 cases per 100,000 population) and the NT the lowest (97.9) (AIHW & AACR, 2004). Residents of the ACT have the highest level of socio-economic status. High socioeconomic status has long been associated with an increased risk of breast cancer as it is an indicator of a range of high-risk factors for breast cancer. These include an earlier onset of menstruation, a greater likelihood of nulliparity, an older average age at birth of first child and later age at menopause. Unfortunately, these risk factors are not easily modifiable through public education or other interventions (Population Health Research Centre, 2003a, 2003b).

1.7.2 Projected Breast Cancer Incidence

The age-standardised incidence rate of breast cancer is expected to remain stable from 2002-2011, at 117.2 per 100,000 population in 2001 and 117.3 per 100,000 in 2011.

Given the increasing numbers of women in the older age groups and the propensity for

breast cancer to affect older women, the number of new cases is expected to increase significantly during this time. The number of new cases is expected to increase by 26% from 11,791 in 2001 to 14,818 in 2011 (AIHW, 2005).

1.7.3 Breast Cancer Mortality

Fortunately, while breast cancer is the most common cancer in women, the survival rates have improved significantly in the past two decades and are relatively high. In the period 1982-1986, one-year survival was estimated at 94.0% and five-year survival at 72.3%. In 1992-1997, one-year survival had risen to 96.4% and five-year survival to 84.0%. There is no relationship between age and survival rates, although survival has significantly increased for women between 30-39 years and 70-79 years by 7.7% and 15.0%, respectively during this time (AIHW & AACR, 2001a).

Nonetheless, breast cancer is still the most common cause of cancer-related death for females. In 2001, 2,612 people died with breast cancer and a further 609 had breast cancer listed as an additional cause of death, meaning breast cancer deaths accounted for 28,540 PYLL. Fortunately, the overall breast mortality rate declined on average 2.2% per year between 1991 and 2001. There were no deaths due to breast cancer in 15 year olds and under, 17.1 deaths per 100,000 population for 15-44 year olds, 56.1 for 44-65 year olds, and 178.9 for those over 65. The ACT reported the highest mortality rates for breast cancer (122.1 deaths per 100,000), followed by SA (117.4), Qld (117.2), Vic (114.9), WA (112.9), NSW (112.3), Tas (104.1), and the NT (97.9) (AIHW & AACR, 2004).

A recalculation of the rates of breast cancer in the ACT was conducted in order to account for the proportion of women from other states travelling to the ACT for treatment and palliative care. The adjusted rates indicate that the breast cancer mortality rates in the ACT are still considerably higher than those of other states and territory. The mortality rate was 31.8 deaths per 100,000 population between 1995 and 1999, which was significantly greater than the national average of 22.0 deaths. The increased rate is probably due to the increased incidence rates previously reported. Investigation of factors that might affect mortality, including screening participation, treatment quality, and high risk lifestyle factors (for example, alcohol consumption), did not

reveal any differences between women residing in and outside the ACT (AIHW & AACR, 2004; Population Health Research Centre, 2003a).

1.7.4 International Comparisons of Breast Cancer Incidence, Mortality and Survival

Overall, breast cancer incidence and mortality is particularly high in most developed countries (for example, Western Europe, the Americas, Australia) but low in less developed countries (Central and Eastern Europe, Asia, Africa) and Japan (although the rate in Japan is rising). Incidence rates in most developed countries have steadily increased since the 1950s, with characteristic inflections in rates in 1990s when routine screening programs were introduced (AIHW & AACR, 2004; Key, Verkasalo, & Banks, 2001; Veronesi, Boyle, Goldhirsch, Orecchia, & Viale, 2005).

The World incidence rate for breast cancer was 35.7 ASR(W), with a higher rate for developed countries (63.2) and lower for underdeveloped countries (23.1). Australia's incidence rate of female breast cancer (82.7) was second behind the United States (91.4). Australia's rate was followed by New Zealand (82.6), Canada (81.8), Western Europe (78.2), the United Kingdom (74.9), Northern Europe (73.2), South-East Asia (56.2), Southern Europe (56.2), and Eastern Europe (49.4) (AIHW & AACR, 2004).

In comparison, mortality rates rose from 1951 to 1990 and declined during the 1990s. Variations in incidence, survival, and mortality rates worldwide is probably due to different levels of exposure to risk factors for the disease and differences in available screening, diagnosis and treatment. The World mortality rate for breast cancer was 12.5 ASR(W), with a higher rate for developed countries (18.6) and lower for underdeveloped countries (9.1) (AIHW & AACR, 2004; Key et al., 2001; Veronesi et al., 2005).

Australia's mortality rate for breast cancer was comparatively low (19.7), ahead of South-East Asia (11.5) and Southern Europe (19.1). The highest rates were reported for the United Kingdom (26.8), New Zealand (25.9), Northern Europe (24.6), Western Europe (23.5), Canada (22.8), the United States (21.2) and Eastern Europe (17.2) (AIHW & AACR, 2004). The five-year survival rate for breast cancer in Australia was placed second with Iceland and Finland (79%) behind the United States (85%). Those

reporting the lowest survival rates included Italy (77%), Europe (73%), Denmark (71%), England/Scotland (66%) and Wales (64%). These estimates were taken from the period from approximately 1987-1991 (AIHW & AACR, 2001a, 2001b).

1.8 Conclusions

Cancer is one of the greatest health challenges facing Australians and will continue to be so in the coming years. Current efforts at screening, diagnosis, and treatment of cancer appear to be effective in slowing the rise in incidence rates and prolonging survival. Of particular interest is breast cancer. Improvements in the screening, treatment, and awareness of breast cancer have meant many women are receiving a diagnosis of EBC and are surviving longer. Nonetheless, it still remains a disease many Australian women will experience. As there is no cure for cancer in the immediate future, it will be vitally important to continue these efforts to improve outcomes. Increasingly important, though, is gaining an understanding of the experience of breast cancer so that those receiving a diagnosis of breast cancer can receive the best possible medical and psychosocial care.

CHAPTER TWO

The Clinical Experience of Breast Cancer

The research conducted on women diagnosed with breast cancer has shown that the clinical experience of the disease is complex. Fortunately, the proliferation of research in the area has gone some way to delineating the nature of the experience. The 'cancer journey' describes the stages people may experience as part of the development, diagnosis and treatment of cancer. For those with EBC, the journey includes the experience of risk factors, screening and detection, diagnosis, treatment (surgery, and adjuvant chemotherapy, radiation therapy and/or adjuvant endocrine therapy), and survival, all of which pose unique challenges for women and their family and friends (National Health and Medical Research Council & National Breast Cancer Centre: NHMRC & NBCC, 2001). This chapter will outline women's typical experience of these stages.

2.1 Risk Factors

The first stage of the cancer journey is the experience of risk factors. In the absence of any known cure, risk factors for the disease have become the focus of research internationally (NHMRC & NBCC, 2001). To date, there exist numerous well-established risk factors for the disease and many more are currently under investigation. These factors are genetic, biological, and environmental.

2.1.1 Genetic Factors

When considering genetic factors, a family history of breast cancer has been shown to strongly increase the risk of developing the disease. Women at a high risk have: 1) three or more first or second degree relatives on the same side of the family with breast or ovarian cancer, or 2) two or more first or second degree relatives on the same side of the family with breast or ovarian cancer including any of the following high risk features: bilateral disease, breast and ovarian cancer in one individual, breast cancer in a male, diagnosis at age 40 or younger, or Jewish people of Ashkenazi origin. Less than 1% of women will be categorised as high risk. The lifetime risk on average of women in this category is usually between 25% and 50% but may be as high as 80% (NHMRC &

NBCC, 2001). This is in comparison with the usual lifetime risk of 9% for Australian women (AIHW & NBCC, 2006).

Women fall into the moderately increased risk category if: 1) one or two first degree relatives were diagnosed with breast cancer before the age of 50, or 2) two first or second degree relatives on the same side of the family were diagnosed with breast or ovarian cancer (without the additional features of the women at potentially high risk described below). Fewer than 4% of women are in the moderately increased risk category and their lifetime risk of developing breast cancer is 12-25% (NHMRC & NBCC, 2001).

Those women who fall into the moderate and high risk categories typically have damage to genes (referred to as a genetic mutation) that suppress the multiplication of cancer cells. Damage to these genes means that cancer cells are able to multiply untempered. The most important and best-established genes involved in this process are the BRCA1 and BRCA2 genes although a range of other genes are currently under investigations (de Jong et al., 2002a). Damage may occur by mutation, amplification or rearrangement, and loss or deletion (Chap, Barsky, Bassett, & Haskell, 2001b). In the general population, about 1 in 1000 women have inherited a mutation in one or other of these genes which increases their risk of breast cancer at least 8-9 fold. BRCA1 and BRCA2 mutations explain only 1-2% of all breast cancer. These mutations can be transmitted through either the maternal or paternal lines (NHMRC & NBCC, 2001). In several ethnic groups, mutations to one or both of these genes are more prevalent. For example, 1 in 44 Ashkenazi Jews carry a mutation, leading to considerably higher incidence of the disease (Chap et al., 2001b).

The discovery of the genetic heritability of breast cancer has led to the development of genetic testing and counselling. Genetic testing and counselling involves screening for BRAC1 and BRAC2 mutations and communicating the results in terms of potential risk of developing breast cancer. At present, genetic testing and counselling is not widely available to women in Australia or overseas due to uncertainty about the extent to which carrier status places a person at risk of breast cancer and concern about the potential and as yet unknown psychological impact of learning one's carrier status. While prospective studies investigating the former issue continue, a number of cross-sectional and short-

term prospective studies have been conducted to address the latter (Daly, 2001; Meiser et al., 2002).

Research has indicated that the period immediately prior to genetic testing and counselling is accompanied by increased general and breast cancer-specific distress but that distress declines after counselling and is accompanied by a more accurate perceived risk. This has been confirmed in a recent meta-analysis (Meiser et al., 2002). Despite the general trend, there appears to be a proportion of people who remain distressed. Recent research has attempted to determine the factors responsible for the increased distress in some people. The potential factors identified to date include gender, family history of breast cancer, whether siblings have received genetic counselling, and the results of siblings' genetic counselling (Smith, West, Croyle, & Botkin, 1999). Unfortunately, most studies have offered genetic testing and counselling to people accompanying a relative to out-patient cancer appointments, making it difficult to distinguish between distress resulting from having a relative with cancer and that resulting from genetic testing and counselling (Meiser et al., 2002; Moyer & Salovey, 1996).

2.1.2 Biological Factors

A number of biological factors has shown an association with breast cancer risk. The most significant of these is age (NHMRC & NBCC, 2001). The increasing incidence of breast cancer with age likely reflects, as for many other cancers, the accumulation of somatic mutations over time (Adami, Signorello, & Trichopoulos, 1998; Chap et al., 2001b). A smaller yet equally consistent risk factor is height, with greater height providing greater risk. Why this is the case is unknown but it is thought that height reflects, to a certain extent, nutritional adequacy in childhood and adolescence which in turn affect levels of oestrogen in the body (Adami et al., 1998; van den Brandt et al., 2000).

Reproductive factors strongly influence a woman's risk of breast cancer, particularly those characteristics of menstrual and childbirth history (NHMRC & NBCC, 2001). While these factors are closely related and therefore the individual effects of each are difficult to delineate, extensive research has been able to do so fairly conclusively (CGHFBC, 2002). These factors are mainly associated with increased lifetime exposure

to oestrogen, an integral risk factor for breast cancer as oestrogen is important in the initiation and progression of breast cancer (Carmichael & Bates, 2004).

An earlier age at menarche and a later age at menopause are associated with increased risk. Earlier age at menarche appears to be associated with a more rapid establishment of regular ovulatory cycles and therefore greater exposure to estrogens throughout the reproductive life of the woman. Menopause involves the cessation of ovarian functioning and the resultant decreased exposure to oestrogen. A later age at menopause means there is a longer period of exposure to oestrogen (Adami et al., 1998).

In general, pregnancy is associated with a reduced risk of breast cancer albeit in a complex manner, while nulliparity is associated with an increased risk. An earlier age at first full-term pregnancy lowers risk but after the age of around 30, a first full-term pregnancy increases breast cancer risk. Subsequent pregnancies have similar but weaker effects on risk. Prolonged lactation provides weak protection, but the effect is small and may be limited to pre-menopausal women with breast cancer. Again, this is due to exposure to oestrogens whereby pregnancy and lactation produce a large increase in endogenous hormones, including oestrogen. Interestingly, there is a transient increase in risk following a pregnancy but this is as yet not understood (Collaborative Group on Hormonal Factors in Breast Cancer: Adami et al., 1998; CGHFBC, 2002).

The use of exogenous hormones, either oral contraceptives (OC) or hormone replacement therapy (HRT) also increases lifetime exposure to oestrogen and as such is associated with a slight increased risk (Adami et al., 1998; Carmichael & Bates, 2004). For the OC, the risk is increased during use but the effect on lifetime risk of breast cancer is small because risk of the disease is low at ages when women commonly take the OC. The excess risk disappears within several years of stopping use. HRT after menopause also appears to elevate risk with increasing duration of use but the excess risk disappears within two years of stopping (Chap et al., 2001b).

2.1.3 Environmental Factors

Environmental factors consistently shown to be associated with increased risk are exposure to ionising radiation, excess weight, and alcohol consumption. Exposure to ionising radiation is strongly associated with an increased risk of breast cancer, even at

low levels of exposure and particularly during adolescence (Veronesi et al., 2005). Evidence for this comes from longitudinal research on populations exposed to ionising radiation to treat medical conditions in childhood and adolescence and to the World War II atomic bomb in Japan (Marcus et al., 2000; Tokunaga et al., 1987).

Excess weight or weight gain is associated with an increased risk in postmenopausal women while the reverse is true for pre-menopausal women. These findings are independent of confounding factors such as breast size, breast density, weight distribution and socio-economic status (Adami et al., 1998; Barnett, 2003). The mechanism for the increased risk in postmenopausal women is not well understood but there are several hypotheses. Overweight women exhibit greater deposits of adipose tissue, lower levels of sex hormone binding globulins, and a higher risk of insulin resistance, all of which confer to increase the levels of oestrogens in the body and therefore increase risk of breast cancer. Alternatively, the protective effect of excess weight in pre-menopausal women may reflect a residual protective effect of greater weight in the early pre-menopausal years, which is a predictor of longer anovular cycles and lower levels of oestrogen. Interestingly, overall and disease-free survivals appear to be lower in obese pre- and postmenopausal women with breast cancer, even after accounting for stage at diagnosis and treatment. Reasons for this are unknown but may be partly due to delayed detection and more rapid growth of metastatic tissue observed in obese women (Carmichael & Bates, 2004; Harvie, Hooper, & Howell, 2003).

Of the many diet-related factors investigated, only alcohol consumption is shown to be modestly associated with increased risk. The nature of the association indicates a dose-response relationship that levels off at higher doses of up to 60g/day or six standard drinks/day and is independent of type of alcohol consumed, intensity of consumption across the lifespan, and other known risk factors. However, a number of limitations in the literature need to be overcome to further confirm the nature of the relationship (Adami et al., 1998; CGHFBC, 2002; Chap et al., 2001b; Singletary & Gapstur, 2001; Smith-Warner et al., 2001).

Fortunately, these environmental factors consist of potentially modifiable behaviours. This means that interventions may be developed and implemented to reduce these behaviours and thereby help to reduce the risk of breast cancer. However, further

research is needed to determine the extent of the risk afforded by these factors and weigh the results with the cost of developing interventions to modify behaviour (Smith-Warner et al., 1998).

2.2 Screening For Breast Cancer

There are three pathways through which women discover they may have EBC: self examination (either by accident or as a result of breast self examination, BSE), clinical examination by a medical professional, and routine mammography screening. Women whose cancer is detected via self and clinical examinations are more likely to have symptoms while those whose cancer is detected via screening mammography are more likely to be asymptomatic (AIHW & AACR, 2004).

2.2.1. Breast Self-Examination and Clinical Examination

Breast self-examination (BSE) and clinical examination by a medical professional both consist of a manual search for changes in breast tissue and are thought to be appealing screening options due to their patient-centred, non-invasive nature (Elmore, Armstrong, Lehman, & Fletcher, 2005). BSE has been widely promoted in the community as an integral technique for identifying breast cancer. Clinical examinations are performed as part of routine care by many medical professionals, particularly general practitioners. Nonetheless, BSE and to a lesser extent clinical examination, have been criticised as effective screening techniques for several reasons.

The overall findings of the empirical literature do not appear to show a clear benefit of BSE in reducing breast cancer mortality (Baxter & Canadian Task Force on Preventive Health, 2001). Some believe BSE and clinical examinations result in unacceptably high rates of false positive findings. Indeed, there are claims that the ineffectiveness of BSE does not warrant the cost of widespread promotion, especially given that rates of BSE are thought to be low. It is also speculated that few medical professionals are as proficient in performing clinical examinations as those participating in clinical trials of their effectiveness (Elmore et al., 2005; Pfeffer, 2004).

For those whose disease is detected via self or clinical examination, the most commonly experienced symptoms reported are lumps in the breast, skin oedema, peau d'orange, and discharge or bleeding (Arndt et al., 2002). The average length of delay between

onset of symptoms and presentation for medical care is 14-16 days, with around two-thirds (64-69%) of women presenting within one month. Of concern is the significant number (14-18%) who delay presentation for one and a half months or more (Arndt et al., 2002; Meechan, Collins, & Petrie, 2003), as patient delay is associated with increased mortality (Coates, 1999; Ramirez et al., 1999; Richards, Smith, Ramirez, Fentiman, & Rubens, 1999). Fortunately, the number of women who delay presentation for medical care has declined over recent years, most likely due to increasing public awareness and openness about breast cancer (Bish, Ramirez, Burgess, & Hunter, 2005).

Limited research has investigated the reasons for delay but so far those reported include the consideration of symptoms as harmless or temporary, and time constraints. Risk factors for extended delay are many and varied and include older age, obesity, having breast symptom other than lump, history of benign breast biopsy, non-participation in routine screening, negative attitudes to GP, not disclosing the symptom to someone else, fears about cancer treatment, and low initial distress on discovering symptom(s). Further replication of findings and extension to other possible risk factors is necessary before specific strategies can be developed and implemented to shorten presentation delay (Arndt et al., 2002; Bish et al., 2005; Hunter, Grunfeld, & Ramirez, 2003; Meechan et al., 2003).

2.2.2 Mammography Screening

In 2002, breast cancer was detected by mammography screening in 2,357 women aged 40 years and over. In other words, mammography screening is responsible for detecting 30% of breast cancers each year (AIHW, 2005; AIHW & NBCC, 2006). The national screening program, BreastScreen Australia, was implemented in 1995. The program is jointly funded by the Australian Commonwealth State and Territory governments and consists of cost-free, fixed or mobile, twice yearly screening and assessment services throughout metropolitan, rural, and remote areas of Australia. The program is aimed specifically at women aged 50-69 years of age without symptoms, although women aged 40-49 years and 70 years and older may attend for screening. Evaluation of the program indicates that early detection is effective in reducing illness and death from breast cancer (AIHW, 2005; AIHW & AACR, 2004).

Nationally, the proportion of women in the target age group (50-69 years) who attended BreastScreen rose from 61% in 1996-1997 to 63% in 1998-1999 and then declined to 61% in 2000-2001. Reasons for the decline in participation are unknown but may be due to improvements in the linking of records to identify women previously screened and to lack of media campaigning in most states. Women aged 40 years and over were increasingly screened by the BreastScreen program with over 1.24 million in 1996-1997 to more than 1.61 million in 2001-2002. A meta-analysis of the effectiveness of routine mammogram suggest that it can reduce mortality in women aged 50-69 years by 20-32% (Taylor, Morrell, Estoesta, & Brassil, 2004). It is difficult to observe the effects of BreastScreen Australia. Any reductions in mortality are probably not observable given the program is only a decade old, women access mammography screening in the private sector, and there are continual changes in treatment efficacy (Giles & Amos, 2003).

The age-standardised program sensitivity for asymptomatic women aged 50-69 years who attended for a first-time screen ranges from 88.9-94.7% and for subsequent screens from 75.0-83.7% (Giles & Amos, 2003). Mammography screening tends to detect breast cancers that are smaller and have more favourable disease characteristics than those detected via other methods. The benefits for women under age 50 years are less clear, although a recent report stresses the need to regularly review the evidence of the effectiveness of mammography screening in women under age 50 years (Senate Community Affairs References Committee, 2005). Again, concern exists that the community practice of mammography screening differs from that in clinical trials (Elmore et al., 2005).

Lower participation rates were evident if women were Indigenous Australians, those of a non-English-speaking background and of high socio-economic status (AIHW, 2005; AIHW & AACR, 2004; Population Health Research Centre, 2003a). Debate continues regarding whether elevated distress facilitates or hinders mammography screening. A recent meta-analysis and review concluded that breast cancer worry increases screening but perhaps in a curvilinear manner (Hay, McCaul, & Magnan, 2006). This is most likely because higher rates of distress have been found to predict over-estimation of breast cancer risk, which would in turn facilitate screening behaviour (Bowen et al., 2003; Lebel et al., 2003). Further research is needed to access those with high levels of

distress, as little is known about the effects of elevated distress on screening (Hay et al., 2006).

Despite the clear advances of mammography screening and high levels of consumer satisfaction (Ekeberg, Skjauff, & Karesen, 2001), the psychosocial impact of breast cancer screening should not be underestimated (Brawley, Prorok, Gohagen, & Kramer, 2001). Women attending mammography screening consistently report elevated levels of anxiety and depression symptoms, although these tend to decline after mammography screening (Ekeberg et al., 2001; van Dooren et al., 2005). Those that are more susceptible to increased distress both prior to and following mammography are younger, over-estimate their risk of breast cancer, conduct frequent BSE, use fewer and/or more avoidant coping strategies, have a history of benign breast biopsies, and are involved in the care of a relative with breast cancer (Heckman et al., 2004; Lebel et al., 2003; McCaul, Branstetter, Schroeder, & Glasgow, 1996; van Dooren et al., 2005).

2.3 Diagnosis of Breast Cancer

2.3.1 Diagnostic Tests

The diagnosis of breast cancer is established by medical history, clinical examination, mammography (with or without ultrasound), and fine needle aspiration or core biopsy. A selection of additional investigations may be performed when clinically indicated and as determined by the medical professionals involved in women's care. These include full blood count and serum biochemistry (including bone marrow, hepatic and renal functioning), chest X-ray, bone scan, liver ultrasound, and chest computed tomography (NHMRC & NBCC, 2001).

Apart from the diagnostic information they provide, these investigations also offer prognostic information. Factors generally associated with a high risk of recurrence and/or death are larger tumour size, higher histological grade, and the presence and number of lymph node metastases. Higher histological grade refers to the extent to which the tumour is differentiated, that is the extent to which it can be distinguished from surrounding normal tissue. Lower grade reflects a well differentiated tumour and higher grades a poorly differentiated tumour. Lymph node metastases refer to the early spread of cancer cells to the nearby lymphoid tissue located under the armpits (NHMRC & NBCC, 2001).

Other potential factors for high risk include early age-at-onset, and negative oestrogen receptor (ER) and progesterone receptor (PR) expression, and high HER2 receptor expression. ER is a receptor protein binds oestrogens and anti-oestrogens and as a result mediates the effects of oestrogens and alters the expression of specific genes. PR is a receptor that binds progestins and anti-progestins. As an oestrogen-induced protein, it can be used as an indicator of ER status. Positive ER and PR statuses also reflect responsiveness to certain therapies (that is, endocrine or hormonal therapies). HER2 is a cell receptor which, when activated, results in the process of cell division. That is, activation of HER2 affects the rate at which tumour cells replicate (Anderson, Jatoi, & Devesa, 2005).

Patients often report that the experience of diagnostic tests can be overwhelming, confusing and occur in a very short space of time (Senate Community Affairs References Committee, 2005). As a result, they have considerable information needs including when they will receive the results of tests, the risks of a diagnosis of breast cancer, and the treatment options for breast cancer (Deane & Degner, 1998).

2.3.2 Receiving the Diagnosis

Once the diagnosis of EBC has been established, this is communicated to the woman and her family. The diagnosis of EBC presents a threat to the woman's life, which often elicits feelings of helplessness and powerlessness and a sense of uncertainty about the future. These feelings may present a significant challenge to women's sense of identity, femininity, body image, self-esteem, psychological wellbeing, sense of independence, relationships with family and friends, and future plans in all areas of life (Turner, Kelly, Swanson, Allison, & Wetzig, 2005).

Indeed, cancer and/or its treatment may disrupt all areas of life. Women report concerns regarding physical and psychological wellbeing, relationships with friends and family, and the ability to continue normal daily activities. Some of the more commonly reported include fear of being stigmatised and rejected once the diagnosis is known, making decisions about medical care, ability to cope with treatment, the effect of the diagnosis and treatment on the rest of the family, disruptions to family, work and social life, and

changes in financial situation due to time off paid work and/or the cost of medical expenses (NHMRC & NBCC, 2001).

When receiving a diagnosis of cancer, patients have reported considerable informational needs. Most patients desire extensive information regarding their diagnosis, prognosis and treatment options (Jenkins, Fallowfield, & Saul, 2001). This is clearly evident in patients' use of a variety of information sources in the period following diagnosis, particularly the internet and popular books (Satterlund, McCaul, & Sandgren, 2003). Patients also have preferences regarding the way in which this information is communicated. They favour a supportive setting and a patient-centred, compassionate, caring, and truthful manner using simple, unambiguous terms (Dowsett et al., 2000; Girgis, Sanson-Fisher, & Schofield, 1999; Parker & Withers, 2001; Senate Community Affairs References Committee, 2005).

Unfortunately, the information needs tend to be at odds with the general quality of doctor-patient communication. Research has revealed that doctor-patient communication is often characterised by terms and euphemisms not well understood by the general public, closed questions, few opportunities for discussion, few questions regarding psychological wellbeing and quality of life, but voluminous information about medical wellbeing (Chapman, Abraham, Jenkins, & Fallowfield, 2003; Fallowfield, 2001; Ford, Fallowfield, & Lewis, 1996).

Not surprisingly, patients have reported low levels of satisfaction with the way in which their diagnosis was communicated (Turner et al., 2005). Such dissatisfaction has the potential to affect their quality of life and satisfaction with subsequent treatment up to three months post-consultation (Gerits & Ce Brabander, 1999; Ong, Visser, Lammes, & de Haes, 2000). Recent attempts to design and implement communication skills training for doctors in the oncology setting has been met with limited success (Fallowfield, Jenkins, Farewell, & Solis-Trapala, 2003; Shilling, Jenkins, & Fallowfield, 2003).

Once a patient receives the diagnosis, they are encouraged to participate in the decision-making process regarding their treatment (Butow et al., 2005). Although most patients desire a lot of information, not all want to use this information as part of an active role in decision-making. In fact, a significant number of patients report that although they

desire much information they would prefer to leave decisions, particularly those regarding treatment, up to the doctor (Fallowfield, 2001; Jansen, Otten, van de Velde, Nortier, & Stiggelbout, 2004; Jenkins et al., 2001). In a study of Australian cancer patients attending their first consultation with their oncologist, 37% reported that they preferred the doctor to take the primary role, 49% preferred an equal role in decision-making, and 14% preferred to take the primary role (Butow, Maclean, Dunn, Tattersall, & Boyer, 1997).

The preference for a passive role in decision-making is understandable. The diagnosis of EBC is a stressful process during which patients often need to gather and understand new medical terms and concepts not previously encountered and consult with several medical specialists. Moreover, this information needs to be mastered in a short period of time, a time in which many patients are still coming to terms with their diagnosis (Moyer & Salovey, 1996; Senate Community Affairs References Committee, 2005). Encouraging an active role in such circumstances may cause undue stress, although it is also possible that patients who prefer a passive role may change their preference when provided with appropriate information and support. Further research is needed to confirm the decision-making preferences of patients and investigate their effects on adjustment to diagnosis and treatment (Butow et al., 1997; Jansen et al., 2004).

2.4 Treatment of Breast Cancer

Unlike women diagnosed with ABC, women with EBC are treated with curative intent. In line with this objective, the treatment of EBC has two aims: to remove as many cancer cells as possible and to destroy any undetected cancer cells in the body to ensure the cancer does not recur. The first aim is achieved via surgery and the second aim through adjuvant treatments such as the administration of cancer-destroying drugs (adjuvant chemotherapy and adjuvant endocrine therapy) and/or X-ray treatment (adjuvant radiation therapy). Surgery and radiation therapy are described as local treatments because they focus on cells at the site of the primary tumour and regional lymph nodes. Chemotherapy and endocrine therapy are systemic treatments because they targets cells throughout the entire body (NHMRC & NBCC, 2001).

To ensure comprehensive and effective treatment, patients with EBC usually undergo several treatment modalities. Treatment often follows a rigid schedule that can last

many months and all modalities have the potential to elicit numerous debilitating side effects which can continue for the duration of treatment and for many months following. The demands of treatment and the side effects of each modality can have a significant impact on body image, levels of psychiatric morbidity, and quality of life. As such, guidelines for medical professionals practicing in Australia (NHMRC & NBCC, 2001) stipulate that women should be fully informed of the short- and long-term effects of all treatments. These effects should be weighed up against the potential benefits of treatment in prolonging survival when doctors and patients are collaboratively deciding on appropriate treatment (Senate Community Affairs References Committee, 2005).

The preparation and receipt of multi-modal treatment often presents patients with what Alder and Bitzer (2003) describe as a “completely ‘new world’ of investigative procedures and treatments...and a multitude of different staff members” (p. 96). While the aim is to provide patients with the best care possible, women often report feeling overwhelmed by the change in their circumstances and feeling out of control in their new role as patient. This can lead to feelings of being lost and lonely in an intimidating and confusing schedule of treatment (Alder & Bitzer, 2003; Senate Community Affairs References Committee, 2005). Indeed, recent awareness of this experience has led to the identification of the need for patient-centred continuity of care throughout all stages of the cancer journey as a priority in cancer care. This is currently being addressed by several government organizations (Cancer Strategies Group, 2001; Senate Community Affairs References Committee, 2005).

2.4.1 Surgical Interventions

Surgical treatment occurs after the necessary diagnostic investigations are completed. Although this can delay surgery by one to two weeks, the information gained provides knowledge integral to the selection of the appropriate surgical procedure. EBC surgery consists of two basic procedures; breast conserving surgery (BCS) and unilateral or bilateral total mastectomy (TM). BCS involves removing the primary tumour including a rim of normal breast tissue around the periphery to ensure all cancer cells of the tumour are removed. When there is a well-defined rim of normal tissue around the tumour this is referred to as a clear margin (NHMRC & NBCC, 2001).

TM involves completely removing the breast tissue while preserving the underlying pectoral muscles. A unilateral TM is when this procedure is conducted on one breast and a bilateral TM is when it is conducted on both breasts. TM is appropriate for women whose tumours extend widely within the breast, have poorly-defined margins which prohibit complete local excision, directly involve the nipple or skin, or for those who do not choose BCS. Many women who receive a TM have the option of undergoing a breast reconstruction at a later date (NHMRC & NBCC, 2001).

In some cases, cancer cells have spread to the lymph nodes in the armpits. Surgical intervention can be extended to include axillary dissection. Axillary dissection is the removal of cells in the armpits. The presence and number of affected axillary lymph nodes are the most powerful indicators of prognosis for primary breast cancer. Axillary dissection carries the risk of lymphedema in the arm, a condition in which excess fluid collected in the lymph nodes and causes swelling (IDG Books Worldwide, 2000). To reduce this risk, a sentinel node biopsy is increasingly carried out to determine whether the lymph nodes are affected (that is, whether they contain cancer cells) and therefore whether axillary dissection is necessary. A sentinel node biopsy consists of sampling the lymph nodes that first receive drainage from the tumour cells. If these nodes are found to be affected, then axillary dissection is performed (NHMRC & NBCC, 2001).

Some women may not only have a primary breast tumour, but also breast diseases that increase the risk of developing a breast tumour. The two most common breast diseases are ductal carcinoma in situ (DCIS) and lobular carcinoma in situ (LCIS). DCIS describes the abnormal proliferation of epithelial cells in the mammary ducts while LCIS is the abnormal proliferation of these cells in the lobules and terminal ducts of the breast. Typically, these breast diseases are also surgically removed along with the primary breast tumour (NHMRC & NBCC, 2001).

The socio-cultural value placed on the breast as a symbol of femininity, sexuality and attractiveness mean that surgical intervention can threaten a woman's sense of body image, self-esteem, sexuality, sexual relationships, and psychological wellbeing. Women may be concerned about their new appearance, friends and family's response to their appearance, partners' or potential partners' acceptance of their appearance,

initiation of first sexual experience following surgery, and the ability to experience sensation in the altered breast (Alder & Bitzer, 2003; Moyer & Salovey, 1996).

To date, research has repeatedly indicated that decrements in these areas are felt more severely by those women undergoing TM compared to TM plus reconstruction and BCS. BCS is associated with less impact on body image and sexuality, higher levels of self-esteem and quality of life, and lower levels of distress from one month and up to five years post-surgery than TM plus reconstruction and TM (Al-Ghazal, Sully, Fallowfield, & Blamey, 2000; Arora et al., 2001; Curran et al., 1998; Ganz et al., 2004; Hartl et al., 2003; Hopwood, Fletcher, Lee, & Al Ghazal, 2001; Meyerowitz, Desmond, Rowland, Wyatt, & Ganz, 1999; Moyer & Salovey, 1996).

Prospective studies have shown that some of the decrements in body image and quality of life decline over time (Arora et al., 2001; Hopwood et al., 2001). Despite this general trend, women vulnerable to decrements in these areas tend to be younger, less optimistic, report little agreement in their relationship, and have lower levels of perceived social support (Abend & Williamson, 2002; Hopwood et al., 2001), although it must not be assumed that physical appearance and sexual functioning are irrelevant for older women.

The majority of women undergoing breast surgery report satisfaction with the resulting cosmetic outcome, but satisfaction is greatest for those undergoing BCS (91%) due to preservation of the breast shape, a better fit of clothing, and avoidance of a prosthesis or reconstructive surgery. Satisfaction is also high following TM plus reconstruction (80%) and less so following TM (73%). Dissatisfaction with the cosmetic outcome can be extremely distressing for patients and has been associated with higher levels of distress, poorer body image and self-esteem, and younger age (Al-Ghazal, Fallowfield, & Blamey, 1999; Al-Ghazal et al., 2000; Hartl et al., 2003; Moyer & Salovey, 1996). Given the significance of these benefits, it is recommended that these issues are discussed with patients when making the choice between BCS, TM, and TM plus reconstruction (NHMRC & NBCC, 2001).

2.4.2 Adjuvant Chemotherapy

After surgery, the appropriate adjuvant treatments are undertaken. Most patients with EBC will receive one or more adjuvant treatments consisting of chemotherapy, radiation therapy and/or endocrine therapy. Overall, the data from clinical trials indicates that using several adjuvant therapies is beneficial because the effects of these therapies on recurrence-free and overall survival are independent. These benefits are evident in all patients aged under 69 years (NHMRC & NBCC, 2001).

Chemotherapy treatment for patients with EBC involves the administration of cytotoxic drugs on an outpatient basis, either in oral form or intravenously, followed by a rest period of one to three weeks. This pattern of administration and rest is known as a cycle and, depending on the regimen prescribed, most patients will undergo between four and eight cycles. Up to the age of 70 years, combination (or multi-agent), moderately prolonged (approximately four to six months) chemotherapy is most effective in extending recurrence-free and overall survival for patients with EBC. Combination chemotherapy lasting several months is more effective than single agent chemotherapy or combined chemotherapy lasting less than one month but no more effective than combined chemotherapy lasting longer. Dose intensity of chemotherapy appears important and should follow standard dosing, as lower doses have poorer outcomes and the evidence for the effectiveness of high-dose chemotherapy is as yet unknown (NHMRC & NBCC, 2001).

The most recent overview data demonstrated a significant improvement in recurrence-free survival with absolute differences in 10-year recurrence-free survival ranging from 35% for women aged less than 50 years and 20% for women aged 50-69 years receiving several months of combination chemotherapy versus those receiving no chemotherapy. The main divergence was observed during the first five years, with curves remaining roughly parallel thereafter. A significant improvement in overall survival was also evident with absolute differences in 10-year overall survival ranging from 27% for those under 50 years or 11% for those aged 50-69 years. Improvements in overall survival were significant in the first five years and continued to improve between five and ten years. The benefits in recurrence-free and overall survival existed regardless of oestrogen and progesterone receptor expression statuses, menopausal status, and receipt

of adjuvant radiation therapy or endocrine therapy (Early Breast Cancer Trialists' Collaborative Group: EBCTCG, 1998; EBCTCG, 2005; NHMRC & NBCC, 2001).

CMF (cyclophosphamide, methotrexate and 5-fluorouracil) was one of the initial combination regimens and has been the standard chemotherapy treatment for many years. Generally CMF has been replaced by AC-based (Anthracycline-containing) regimens as these appear superior in improving recurrence-free and overall survival. Ten-year recurrence-free and overall survival for AC regimens yielded a further 12% proportional reduction in recurrence and 11% in mortality than CMF regimens. However, AC regimes are associated with increased toxicity, including alopecia (hair loss), febrile neutropenia, and increased risk of cardiac toxicity. Febrile neutropenia describes a condition in which bone marrow functioning is compromised, leaving the patient at risk of infection (EBCTCG, 1998, 2005; NHMRC & NBCC, 2001).

Adjuvant chemotherapy for EBC can cause a number of side effects, all of which may impact on quality of life, particularly physical, cognitive, emotional and social domains. Almost half of patients report severe disruption to their lives (Given et al., 2004; Lee, Dibble, Pickett, & Luce, 2005; Osoba et al., 1997). The most frequently reported are nausea and vomiting (NHMRC & NBCC, 2001). Acute nausea and vomiting refers to that occurring during the 24 hours after chemotherapy and delayed nausea and vomiting occurs after this period. Despite the use of anti-emetics, acute nausea is experienced by at least 45% and delayed nausea by 31%. Acute vomiting is experienced by at least 15% of patients and delayed vomiting by 28% (Lee et al., 2005). The worst vomiting usually occurs in the first three days following chemotherapy infusion (Dibble, Casey, Nussey, Israel, & Luce, 2004; Kris, Roila, De Mulder, & Marty, 1998).

Effective early control of chemotherapy induced nausea and vomiting is vital as it can worsen if not dealt with immediately, in some cases leading to the development of anticipatory nausea and vomiting. This is when patients begin to experience nausea and vomiting prior to receiving a chemotherapy infusion. The mechanisms for anticipatory nausea and vomiting are not yet well understood (Carey & Burish, 1988). In the worst instance, uncontrolled nausea and vomiting may contribute to the decision to delay or even withdraw from treatment.

The most effective medications are 5HT₃ receptor antagonists and corticosteroids, either via oral or intravenous administration prior to initiation of treatment. The ‘gold standards’ for anti-emetic treatment include a corticosteroid for mildly emetogenic regimens, and both a 5HT₃ receptor antagonist and a corticosteroid in moderately to highly emetogenic regimens. The addition of an appetitant or an anxiolytic six to twelve hours prior to chemotherapy infusion is recommended when anticipatory nausea and/or vomiting are experienced or when the use of both a 5HT₃ antagonist and corticosteroid is ineffective (Bartlett & Koczwara, 2002; Dibble et al., 2004; Gandara et al., 1998; Kris et al., 1998; Oettle & Riess, 2001). Given that the emetogenic potential of regimens is largely based on expert consensus (Bartlett & Koczwara, 2002), and a range of other non-medical factors are implicated in the development of nausea and vomiting (Montgomery & Bovbjerg, 2001), anti-emetic treatment should also be based on patients’ medical history and individual requirements (Oettle & Riess, 2001).

Fatigue is also commonly experienced and in some cases, fatigue may become a chronic problem. Patients report experiencing fatigue across cycles and a decline after treatment but difficulties in the measurement of fatigue and the tendency to measure it across a selection of cycles makes it difficult to draw firm conclusions about patients’ experience of it (Bower et al., 2000; de Jong, Courtens, Abu-Saad, & Schouten, 2002b; Sadler & Jacobsen, 2001). In a similar vein, patients may also report experiencing impaired cognitive abilities during chemotherapy treatment, including poor concentration and memory, but this usually resolves upon completion. Investigations are underway to determine whether these impairments are subjective or objective, and whether they can be attributed to the chemotherapeutic drugs or co-morbid fatigue and/or psychological distress (Castellon, Silverman, & Ganz, 2005; Falleti, Sanfilippo, Maruff, Weih, & Phillips, 2005; Jansen, Miaskowski, Dodd, & Dowling, 2005; Schagen et al., 1999).

Temporary but significant alopecia requiring a wig is common following anthracyclines although less common in women having CMF. Alopecia may be very distressing for the woman and her family as it is a highly visible reminder of the cancer and can negatively impact on body image and identity. Although hair usually grows back within three months of completing treatment, it may have a different texture and be curlier than before (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997).

Chemotherapy has been associated with impairment in sexual functioning during and following treatment (Arora et al., 2001; Dow, Ferrell, Leigh, Ly, & Gulasekaram, 1996; Meyerowitz et al., 1999). The most common aspects affected include fatigue, breast sensitivity, vaginal atrophy, decreased vaginal lubrication, decreased libido, and body image problems (Ganz et al., 2004; Meyerowitz et al., 1999; Takahashi & Kai, 2005). Some of these symptoms may occur as a result of menopause, a common consequence of chemotherapy (McPhail, 1999; Meyerowitz et al., 1999; Young-McCaughan, 1996). Despite these difficulties, more than 80% of patients reported that they were never asked by health professionals about sexual functioning and most were reluctant to raise it (Young-McCaughan, 1996).

Less common side effects experienced during chemotherapy include mouth ulcers, diarrhoea, conjunctivitis, and chemical cystitis. Rare side effects include febrile neutropenia, infection, and venous thromboembolism. In some cases, patients who have previously experienced febrile neutropenia in response to chemotherapy treatment are provided with medication to boost their bone marrow functioning and therefore avoid the future development of febrile neutropenia. This medication is known as Granulocyte-colony stimulating factors (GCSF) support. The risk of death from adjuvant chemotherapy is very low. Cardiac failure is associated with higher cumulative doses of AC regimens. In the longer term, therapy-induced leukaemia can occur, especially after AC regimens, but is rare (NHMRC & NBCC, 2001).

2.4.3 Radiation Therapy

Radiation therapy involves the direction of a moderate dose of ionising radiations at the breast and/or chest wall, often followed by a higher dose (or boost) to the site of excision. The boost allows the delivery of a higher dose to a small volume within which the risk of residual cancer cells is greatest. Radiation therapy can destroy sizeable masses of tumour cells while preserving the structure, function and cosmesis of normal tissues. Radiation therapy is most effective when the number of cancer cells is limited and the tumour has not destroyed the adjacent tissues so that only modest doses of radiation are required and tissue can be preserved. The disadvantage is that it requires daily administration for ten to twenty minutes on an outpatient basis for five to six weeks (Parker & Withers, 2001).

Radiation therapy significantly increases recurrence-free and overall survival, independent of other treatment received. The majority of recurrences occur in the first five years with an absolute risk of recurrence of 7% for those receiving radiotherapy versus 26% for those who did not receive radiotherapy. The 5-year risk of mortality is less extreme than the risk of recurrence but is not significant. However, the 15-year risk of mortality is significant with 30.5% for those receiving radiotherapy compared to 35.9% for those not receiving radiotherapy. Greatest benefit in 5-year risk of recurrence was evident in women who were younger (under 50 years), had larger tumours (>50mm), poorly differentiated tumours and tumours that involved the skin or chest wall (Clarke et al., 2005; Veronesi et al., 2005).

The side effects of radiotherapy are a function of the anatomical extent of the radiation fields, the field arrangement, the fraction size, and the total dose. Patients most commonly report redness, soreness, alopecia, tight skin, discomfort or pain to the treated breast, and sometimes lymphedema (if the axillary lymph nodes are irradiated). Redness, soreness and alopecia may last up to one to two weeks post-treatment but tight skin, discomfort, pain and lymphedema may occur for many months or years (NHMRC & NBCC, 2001).

A number of rare side effects have been reported and include osteitis (inflammation or brittleness), radiation pneumonitis (inflammation of the lungs), and in the longer term, brachial plexopathy (decreased movement or sensation in the arm). A risk of cardiac damage exists but is unlikely given recent trends to irradiate only the chest wall and to avoid high doses. Other causes of mortality, particularly resulting from vascular problems, may occur in patients who are older or have a low risk of recurrence (NHMRC & NBCC, 2001).

2.4.4 Endocrine Therapy

Endocrine therapy for EBC involves taking an oral dose of a medication that opposes the effect of oestrogen in the body. The medications used in endocrine therapy work to oppose oestrogen in different ways. At present, Tamoxifen (20mg daily) is the most widely studied and commonly prescribed form of endocrine therapy for EBC patients. For those with oestrogen receptor-positive tumours, five years of Tamoxifen significantly increases recurrence-free and overall survival. The 15-year absolute risk of

recurrence for those receiving Tamoxifen is 33.2% compared to 45.0% for those not receiving Tamoxifen, and the 15-year absolute risk of mortality is 25.6% compared to 34.8%. The annual increase in recurrence-free and overall survival are similar during years 0-4 and 5-14 so the cumulative reduction in mortality is more than twice as big at year fifteen as at five years post-diagnosis. These benefits are independent of age, progesterone receptor status, other tumour characteristics and other treatments received. Trials show that five years of Tamoxifen is more effective than one or two years. Mortality from other causes is not significantly increased (Cuzick et al., 2002; EBCTCG, 1998, 2005; NHMRC & NBCC, 2001).

The potential side effects of Tamoxifen include hot flushes, dyspareunia, vasocongestion, and decreased vaginal lubrication. Ocular toxicity and ocular changes have been reported but are usually asymptomatic (NHMRC & NBCC, 2001). The risk of osteoporosis is elevated for pre-menopausal women and can lead to bone fractures (Mrozek & Shapiro, 2005). Increased rates of pulmonary embolism, stroke and DVT were elevated in women aged 50 years and over following treatment with tamoxifen (NHMRC & NBCC, 2001). Therefore, endocrine therapy is contraindicated in women at high risk of thromboembolic disease (Cuzick et al., 2002). A more significant problem is the increased incidence of endometrial cancer in post-menopausal women. The exact risk in the Australian context is uncertain, but overseas reports show the incidence of endometrial cancer was increased about 2.5-fold. For most women, the protective effects of Tamoxifen against the recurrence of breast cancer will vastly outweigh the increased risk of side effects (NHMRC & NBCC, 2001).

More recently, alternative endocrine therapies have been investigated, the most common being Anastrozole (1mg daily). Recent findings suggest that Anastrozole alone is significantly more effective in improving recurrence-free and overall survival after four years than either Tamoxifen or a combination of Anastrozole and Tamoxifen.

Anastrozole demonstrated significantly lower rates of contralateral breast cancer and was better tolerated with respect to endometrial cancer, vaginal bleeding and discharge, cerebrovascular events, venous thromboembolic events and hot flushes than Tamoxifen. However, Tamoxifen showed significantly lower rates of musculoskeletal disorders and fractures. Longer follow-up is required before a final benefit and risk assessment can be

made (Arimidex, Tamoxifen Alone or In Combination Trialists' Group: ATACTG, 2002, 2003).

2.5. *Survivorship*

The high incidence and survival rates of EBC makes women with a history of breast cancer one of the largest group of cancer survivors. Indeed, the number of women surviving a diagnosis of breast cancer is increasing, from 72% for the period of 1982-1986 to 84% for 1992-1997 for the five years following diagnosis (AIHW & AACR, 2001a). Until recently, little was known about the experience of surviving a diagnosis of EBC with medical professionals relying on anecdotal evidence to inform women of the experience of survivorship (Ganz et al., 2004). However, increasing improvements in EBC survival rates, improved access to screening, increasing public awareness and consumer activities, and widespread media attention have led to increased attention to survivorship (Dow et al., 1996) and its identification as a priority for community services and research (Vivar & McQueen, 2005).

The potential benefit of a comprehensive understanding of the experience of survivorship in women with a history of EBC is significant. It will enable health professionals to have an accurate understanding of the impact of and adjustment to diagnosis and treatment, will help them provide future patients with more specific information about what to expect from their diagnosis and treatment, and to identify and develop or maintain necessary psychosocial interventions (Ganz et al., 2004; Holzner et al., 2001; Mosconi, Colozza, De Laurentiis, De Placido, & Maltoni, 2001).

While adjustment to survivorship is widely considered a process (Breaden, 1997), there are many consistencies in the issues reported by women with a history of EBC in the literature. Overall, women report good quality of life and some benefits of their experience with EBC, all of which continue with time (Dow et al., 1996). Nonetheless, issues are evident in the domains of physical and psychological wellbeing, spirituality, relationship with health care providers, and social and role functioning.

Women report a range of residual side effects from treatment including fatigue, nausea, pain, weight gain, forgetfulness, fertility problems, and menopausal symptoms (Ferrell et al., 1996; Ferrell et al., 1997; Ferrell, Grant, Funk, Otis-Green, & Garcia, 1998; Ganz

et al., 2004; Thomas-MacLean, 2005; Vivar & McQueen, 2005). While some of these symptoms decline with time, they still have a significant negative impact on quality of life, sometimes up to five years post-diagnosis (Bower et al., 2000; Ganz et al., 2004; Helgeson & Tomich, 2005). The symptoms may also cause concern in women who believe they indicate a recurrence of the disease. Some women reported that their attempts to obtain treatment for these side effects and clarify this concern were dismissed by health professionals (Ferrell et al., 1997; Vivar & McQueen, 2005).

Changes to the body following treatment may have a number of effects including eliciting feelings of loss and grief, concern about management of new appearance (e.g. use of prosthesis) (Thomas-MacLean, 2005), and a decline in sexuality and sexual functioning. The negative impact in sexual functioning is attributed to concern about appearance as well as the development of menopausal symptoms known to affect ability to engage in sexual activities (Ferrell et al., 1997; McPhail, 1999). This is particularly the case for women undergoing chemotherapy who may experience a change in menopausal status. This change may be considered a permanent and potentially devastating side effect, especially for those women who wish to have children (Dow et al., 1996; Ferrell et al., 1997; Ganz et al., 2002; Knobf, 2002; Meyerowitz et al., 1999; Wimberly, Carver, Laurenceau, Harris, & Antoni, 2005); Senate Community Affairs References Committee, 2005). Women may feel embarrassed and guilty to be concerned about their physical appearance and sexual functioning when they should be grateful for being alive (Ferrell et al., 1997, 1998).

Although there may be a tendency for health care professionals to focus on physical wellbeing, it is evident that psychological wellbeing during survivorship are equally important (Ferrell et al., 1996). Women may describe intense fears of recurrence and dying, a sense of uncertainty about the future, and the feelings of loss of control over their health and lives as the most distressing and consuming aspects of survivorship (Curran et al., 1998; Dow et al., 1996; Tomich & Helgeson, 2002). These concerns are particularly evident in young women who perhaps have different expectations of disease and disability and therefore feel a greater sense of deprivation in their life compared with older women (Wenzel et al., 1999). Unfortunately, these concerns are triggered by being around others with cancer, hearing about cancer, and physical reminders of cancer, all of which occur during the course of routine follow-up (Johnson Vickberg,

2001). In some cases, intense fears of recurrence can lead to preoccupation with physical wellbeing (Kissane et al., 1997).

However, women report tempering these concerns with a renewed sense of purpose and satisfaction with life as a result of a dramatic shift in their life priorities and life meaning (Dow et al., 1996; Ferrell et al., 1997; Tomich & Helgeson, 2002; Wyatt, Kurtz, & Liken, 1993). Spirituality was raised by some women as an important support, either through formal religious practices or informal existential faith or beliefs, and was an important predictor of overall quality of life (Brady, Peterman, Fitchett, Mo, & Cella, 1999; Dow et al., 1996; Ferrell et al., 1996; Ferrell et al., 1997, 1998; Tomich & Helgeson, 2002).

Some women continue to report symptoms of anxiety and depression after completion of treatment but these symptoms typically decline with time (Ganz et al., 2002). Given the ongoing presence of physical side effects, the importance of distinguishing depressive symptoms is still pertinent in survivorship (Dow et al., 1996). The few women who develop anxiety and depressive symptoms for the first time in survivorship often report surprise, particularly if they feel they coped well during their diagnosis and treatment (Ganz et al., 2004).

An area of great concern is the impact of EBC on the family (Dow et al., 1996; Ferrell et al., 1997). Women may be concerned that the needs of family members are not met, feel guilty about the possibility of 'passing it on' to daughters or having survived when many family and friends have not (Ferrell et al., 1997, 1998; Ganz et al., 2004), feel hurt by their rejection by certain friends, and have a decreased tolerance for the minor complaints of others (Wyatt et al., 1993). Nonetheless, women reported the significance of support and acceptance from family and friends in their improvement (Dow et al., 1996).

This sense of support extended to relationships with health professionals. Women reported having confidence in their health professionals and found their continued access to them provided significant reassurance regarding their ongoing health status (Breaden, 1997; Ganz et al., 2004; Vivar & McQueen, 2005; Wyatt et al., 1993). Indeed, patients report that one of the most difficult stages in the cancer journey is when

they complete treatment and are no longer in close contact with health professionals. They believe it was not until this point in their experience that they fully considered the meaning of their diagnosis, treatment, and future plans (Lethborg & Kissane, 2003).

The majority of women feel that their levels of functioning in normal daily life return to those before diagnosis within around two years of diagnosis (Dow et al., 1996; Ferrell et al., 1997, 1998; Ganz et al., 2002) and that their future plans for education, employment and leisure were unaffected by the breast cancer experience (Ganz et al., 2002). Most concerns about role functioning centred on the ability to return to the workplace, particularly whether they would be accepted and physically able to cope. This may be of particular concern for those women who experienced significant out-of-pocket expenses as a result of diagnosis and treatment (Butler & Howarth, 1999; Lauzier et al., 2005). These expenses can be felt by the whole family for a considerable period of time after completing treatment. On the other hand, returning to work eased concerns about the financial impact of illness and helped return a sense of normalcy (Breaden, 1997; Dow et al., 1996; Ferrell et al., 1997, 1998; Rendle, 1997).

It should be noted that research into survivorship is plagued by shortcomings, all of which must be overcome to better understand the challenges and benefits experienced in survivorship by women with a history of EBC. Theoretical issues include variation in the definition of quality of life (QOL) and the tendency to focus on a narrow selection of QOL domains (for example, physical and psychological wellbeing) to the exclusion of others (for example, sexual functioning, role functioning) (Gotay & Muraoka, 1998; Mosconi et al., 2001; Tomich & Helgeson, 2002; Vivar & McQueen, 2005).

Methodological issues include small sample sizes, large variation in time since diagnosis, the description of survival according to time since diagnosis rather than end of treatment, failure to account for those patients receiving daily Tamoxifen, use of ad hoc QOL instruments developed for a specific study instead of well-known standardised and validated questionnaires, and the failure to use control groups to determine the extent to which declines are due to the normal process of ageing (Gotay & Muraoka, 1998; Mosconi et al., 2001; Tomich & Helgeson, 2002; Vivar & McQueen, 2005). Clearly, research will need to overcome these theoretical and methodological issues to

clarify our understanding of survivorship and to extend this knowledge to efforts at rehabilitation (Lethborg & Kissane, 2003).

2.6 Psychological Distress

It is apparent that the diagnosis and treatment of EBC is challenging on many fronts. Treatment is lengthy, consists of several modalities with their own rigid procedures and side effects, requires significant commitment from patients, and may affect several aspects of quality of life. Thus, it is not surprising that many women report feelings of distress at one or more stages of their treatment. Distress commonly occurs at the time of diagnosis, awaiting biopsy results, after diagnosis while waiting for treatment, during any prolonged wait for treatment, following discharge from hospital, and following completion of treatment. Women may be more vulnerable to elevated levels of distress if they are younger, single, of lower socio-economic status, have poor romantic relationships and social support, a past history of psychiatric illness, cumulative stressful life events or poorer physical health (Alder & Bitzer, 2003; Compas & Luecken, 2002; Dausch et al., 2004; Osborne, Elsworth, & Hopper, 2003; Pasacrete, 1997).

Although the majority of women will adjust to their diagnosis and treatment, a significant proportion will go on to develop a psychiatric disorder which may require pharmacological and/or psychological interventions (NHMRC & NBCC, 2001). It is well established that much of this psychological morbidity goes undetected (Badger, Braden, Mishel, & Longman, 2004; Berard, Boermeester, & Viljoen, 1998; Nordin, Berglund, Glimelius, & Sjoden, 2001; Payne, Hoffman, Theodoulou, Dosik, & Massie, 1999). In a recent large-scale study of clinicians' ability to detect patients with psychiatric morbidity, results indicated that clinicians' had a sensitivity of 29%, specificity of 85%, and misclassification of 35% (Fallowfield, 2001).

Health care professionals may fail to detect distress due to time constraints during outpatient visits, concern about the treatment of the disease and any immediate medical issues, concern about the cost and reimbursement of services, and access to appropriate mental health referral services. Furthermore, patients may be reluctant to report distress due to a lack of symptom awareness, fear of the stigma associated with mental illness, lack of support from family and friends, reactions of stoicism or hopelessness, and fears

of appearing weak and losing their health care professionals' support (Croyle & Rowland, 2003).

Undetected and untreated patient distress can have a deleterious impact on medical outcomes due to lack of compliance with treatment plans, greater side effect burden, slower recovery, decreased patient satisfaction, and reduced quality of life, all of which serve to inflate health care costs (Badger et al., 2004; Dausch et al., 2004; Girgis & Boyes, 2005; Pasacrete, 1997). Consequently, most psychosocial care is offered reactively, that is, when the patient is in a state of crisis (Girgis & Boyes, 2005). In an effort to reverse this trend, the guidelines for medical professionals in Australia recommend that doctors enquire about patients' mood and adjustment (NHMRC & NBCC, 2001).

To determine the prevalence of psychiatric disorders, the clinical interview is considered the 'gold standard'. Current estimates of the prevalence of anxiety and depressive disorders in women with breast cancer vary but it has been estimated that 11-50% of women meet criteria for a diagnosis of major depression and 9-37% for anxiety disorder at three to four months following diagnosis (Hall, A'Hern, & Fallowfield, 1999; Love, Kissane, Bloch, & Clarke, 2002; Pasacrete, 1997). Typically, the prevalence of anxiety and depressive disorders declines over the ensuing months with estimates one to two years following diagnosis of 4-18% for depression and 3-14% for anxiety (Dausch et al., 2004; Grassi, Malacarne, Maestri, & Ramelli, 1997; Morasso et al., 2001). These rates are similar to those experienced by the general population (Compas & Luecken, 2002; Dausch et al., 2004; Pasacrete, 1997; Payne et al., 1999; Waller, Compas, Hollon, & Beckjord, 2005).

More commonly, investigators have considered the prevalence of anxiety and depressive symptoms in women with breast cancer by employing self-report measures. The estimates indicate that while a number of women develop an anxiety or depressive disorder, many more will experience levels of anxiety and depressive symptoms significantly higher than the general population (Compas & Luecken, 2002; Dausch et al., 2004). According to widely accepted measures, levels of anxiety and depressive symptoms indicative of anxiety and depression cases are estimated at 14-48% and 3-34% respectively, within three months of diagnosis (Dausch et al., 2004; Groenvold et

al., 1999; Hall et al., 1999; Love et al., 2002; Montazeri et al., 2000; Nosarti, Roberts, Crayford, McKenzie, & David, 2002), and 22-28% and 3-19% respectively, at one year or more (Nosarti et al., 2002; Osborne et al., 2003; Rodgers, Martin, Morse, Kendell, & Verrill, 2005; Schou, Ekeberg, Ruland, Sandvik, & Karesen, 2004), respectively.

In spite of the importance of accurately assessing the prevalence of anxiety and depression in patients with breast cancer, theoretical and methodological challenges have hampered efforts to do so and are reflected in the varying rates reported (Dausch et al., 2004). The symptoms of anxiety and depression that often accompany bad news may be assumed to be appropriate but this may not be the case when these symptoms persist or worsen over time (Croyle & Rowland, 2003). Thus, the boundary between normal response and clinical symptoms remains undefined (Pasacrete, 1997). It is widely acknowledged that the characteristic symptoms of psychiatric disorders and those experienced as a result of the disease and its treatment overlap significantly. Therefore it can be difficult to distinguish between the two (Bower et al., 2000; Croyle & Rowland, 2003; Nordin et al., 2001; Pasacrete, 1997).

Investigation into the accuracy of reliance on alternative criteria for psychiatric disorders in patients may be useful. For example, fatigue and disruptions in sleep and appetite are depressive symptoms that may be considered consequences of the disease and treatment. Alternative depressive symptoms to be considered include indecisiveness, guilt, helplessness, worthlessness and suicidality. These are all symptoms included in the diagnostic criteria of depression in the widely accepted and used diagnostic manuals of the latest Diagnostic and Statistical Manual (American Psychiatric Association, 1994) and International Classification of Diseases (World Health Organization, 1992).

Moreover, the association between the diagnosis and treatment of breast cancer and the depression symptoms may vary according to time since diagnosis, type and stage of EBC, concurrent treatment, and medical co-morbidities. Thus, the assessment of seemingly homogenous samples of women with EBC may contain confounding variables that affect the prevalence rates of disorders reported (Compas & Luecken, 2002; Croyle & Rowland, 2003; Dausch et al., 2004; Nordin et al., 2001; Pasacrete, 1997). The error in prevalence estimates may be exaggerated by a reliance on a single

assessment of psychiatric morbidity (Dausch et al., 2004). Lastly, a variety of structured clinical interviews have been utilised and may account for the broad range in estimates (Dausch et al., 2004; Grassi et al., 1997; Hall et al., 1999; Morasso et al., 2001; Pasacrete, 1997).

While the focus on the psychiatric disorders of anxiety and depression are important, it has come at the cost of investigation of other equally distressing, debilitating, and potentially elevated disorders such as adjustment disorder, post-traumatic stress disorder (PTSD) and acute stress disorder (ASD). Recent research has attempted to estimate the prevalence of these disorders. Rates of around 2-24% for adjustment disorder, 3-5% for PTSD and 2% ASD have been reported in women at least six months after diagnosis (Dausch et al., 2004; Grassi et al., 1997; Morasso et al., 2001). Again, consideration of the prevalence of the symptoms of PTSD and ASD reveal much higher rates (Green et al., 1998; Turner et al., 2005). More research is needed to determine the prevalence of these disorders in patients with EBC in order to gain a comprehensive understanding of the nature of distress in women dealing with the disease and the ways in which they might be best supported (Dausch et al., 2004; Love et al., 2002; Payne et al., 1999).

Not only can the diagnosis and treatment of breast cancer affect a woman's psychological wellbeing, it can also affect that of her partner. Research investigating symptoms of anxiety and depression in partners of women diagnosed with breast cancer reveal that they also experience elevated levels of symptoms (Ben-Zur, Gilbar, & Lev, 2001). This is probably due to offering much needed informational, instrumental, and emotional support to partners, perhaps to the neglect of their own support needs (Moyer & Salovey, 1996). Women's and partners' levels of symptoms have been found to affect the quality of the relationship. Lack of perceived support, closeness, and agreement as well as discrepancies in the way in which diagnosis and treatment challenges are coped with, all lead to increased symptoms (Barnoy, Bar-Tal, & Zisser, 2006; Ben-Zur et al., 2001). These findings have led to the development and implementation of couple-focused interventions, so far with limited success (Cochrane & Lewis, 2005).

Little research has been conducted to determine the effect on the children or family of women with breast cancer, although speculation and suggestion are common. It is thought that the impact of breast cancer on children depends largely on their

developmental stage, signalling a need to provide information and support appropriate to the level of understanding. It is considered that the promotion and maintenance of open communication and expression of thoughts and feelings in the home setting is helpful for all members of the family, including women diagnosed with breast cancer (Wimberly et al., 2005).

To combat the levels of psychological distress encountered by women diagnosed with and treated for breast cancer, there is a plethora of support organizations. At recent count, there were more than 100 government and non-government organizations involved in cancer policy, treatment and support in Australia (Cancer Strategies Group, 2001; Senate Community Affairs References Committee, 2005). This, together with the large volume of information available on breast cancer, signals an understanding and openness about the significant distress and challenges engendered in the diagnosis and treatment of breast cancer (Moyer & Salovey, 1996). It should be noted, however, that difficulties accessing these services are widely acknowledged and are currently being addressed by several government organisations (Cancer Strategies Group, 2001; Senate Community Affairs References Committee, 2005).

2.7 Conclusions

The clinical experience of breast cancer is complex and challenging. It involves a journey in which patients are faced with a series of diagnostic tests, receipt of a diagnosis and prognosis, decision-making regarding appropriate treatment, the receipt of multi-modal treatments, and the uncertainty of survival. All of these present unique challenges that have the potential to result in significant declines in physical and psychological wellbeing (Moyer & Salovey, 1996). While the research outlined has effectively delineated the many stressful aspects of the cancer journey, it is now necessary to understand the way in which women come to experience stress and cope with this stress (Butow, Coates, & Dunn, 2000a).

CHAPTER THREE

The History of Stress and Coping Theory

The experience and ways of coping with stress have long been implicated in physical and psychological wellbeing. Understanding how women diagnosed with EBC experience stress and cope with this stress may provide invaluable insights into the wide range of physical and psychological wellbeing reported during the EBC journey. If this is the case, medical and allied health professionals may be able to develop and implement supportive medical and psychosocial interventions aimed at enhancing wellbeing. First, it is necessary to gain an understanding of the nature of stress and coping. The following chapter aims to outline the most widely acknowledged stress and coping theories in the psychological literature.

3.1 Approaches to Stress

Stress is a concept that has secured the attention of diverse disciplines. As a result, a range of definitions and theories of stress have been proposed. In the area of psychology and health, three main theories of stress have shaped our understanding of the concept and guided research. In order to understand the way in which stress is thought to operate, the following section presents the three main theories of stress; Cannon's (1915, 1929) Fight-or-Flight Response theory, Selye's (1956, 1976) General Adaptation Syndrome theory, and Lazarus and Folkman's (1984) Cognitive-Transactional theory of stress.

3.1.1 Fight-Or-Flight Response Theory

In 1915, Cannon described the human and animal bodies' experience of stress. He outlined many physiological processes of the body that are activated in order to maintain physical wellbeing. For example, he outlined the role of hunger and thirst in activating processes to ensure the body has sufficient energy to function effectively. It is in this context that Cannon coined the term 'homeostasis', which refers to the body's attempts to maintain a certain level of wellbeing (Caltabiano, Byrne, Martin, & Sarafino, 2002; Cannon, 1915; Selye, 1976).

Cannon also outlined what happened to the body's physiological processes in a stressful situation. When faced with a stressful situation, he explained that the body's sympathetic nervous system was activated to arouse the body, allowing the body to attack the threat or flee from it. In this way, the fight-or-flight response consists of both benefits and costs to the body. It is an adaptive response in that it allows the avoidance of danger but the state of arousal necessary to avoid the threat can damage the body and lead to death (Caltabiano et al., 2002; Cannon, 1915; Selye, 1976). In other words, Cannon conceptualises stress as a response of the body to objective, external demands (Lazarus & Folkman, 1984).

3.1.2 General Adaptation Syndrome Theory

Several decades later, Selye (1956; 1976) outlined the General Adaptation Syndrome (GAS) theory of stress. The GAS theory again views stress as a reaction of the body to external demands but describes the response in more detail. The GAS consists of three stages in which the body defends itself against threat: the alarm reaction, resistance, and exhaustion. The alarm reaction describes the perception of threat and the process of initial arousal when the body prepares to defend itself. Resistance consists of the use of physiological resources to defend against the threat as it is experienced. If the threat continues, exhaustion occurs and involves the depletion of the body's physiological resources. This depletion can be reversible or irreversible. In cases of mild threat, the body's physiological resources are depleted so that the body is weakened. However, when the threat ceases, the body is able to restore its resources thereby reversing any damage. In cases of prolonged or intense threat, the body's physiological resources are depleted so much that injury or in some cases, death occurs (Selye, 1956, 1976, 1993).

Not all stages are experienced in response to a threat. The GAS theory states that most threats are of limited duration and intensity and as such, typically only the first two stages are experienced. Hence depletion is reversible. A later revision of the GAS proposed the concepts of eustress and distress. Selye (1976) specified that when the threat necessitates the first two stages, that is the threat provides a challenge to the body, the stress experienced is referred to as eustress. When the threat involves all three stages and damages the body, the stress experienced is referred to as distress (Selye, 1956, 1976).

Selye's (1956, 1976) theory signalled an extension of Cannon's (1929) theory in two main ways. First, the GAS specified in more detail the physiological processes that enable the body to prepare and defend itself against threat. This detail provided a series of objective indices of stress that have been widely utilised in subsequent theory and research. Second, the specification of three main stages of the stress response indicated the finite capacity of the body to deal with stress (Caltabiano et al., 2002).

Since its inception, the GAS has attracted several criticisms. These criticisms have focused on two main omissions: the failure to consider the strength of the response to stressful situations and the role of cognitive appraisal processes in the perception of situations as stressful. Selye (1956, 1976) states that the body's response to a stressful situation is the same, regardless of the nature of the situation. In fact, it has been suggested that some stressful situations elicit stronger emotional responses than others (Caltabiano et al., 2002). Selye also states that situations are inherently stressful and cause the body to respond. However, it has also been suggested that people differ in the extent to which they consider a situation to be stressful. Failure to consider the nature of this appraisal may result in all situations to which people have to adapt being considered stressful situations (Caltabiano et al., 2002; Lazarus & Folkman, 1984; Mormede, 1990).

3.1.3 Cognitive Transactional Theory

The cognitive transactional theory of stress moves beyond the view that stress is the response of a person to an objective, external demands and instead considers the psychological processes influencing the experience of stress (Stone, Greenberg, Kennedy-Moore, & Newman, 1991). The transactional theory outlines a reciprocal relationship between a person and a stressful situation such that stress occurs when a situation is perceived to challenge or exceed the resources available to deal with the situation and threaten wellbeing. The reciprocal relationship in which a transaction between the person and the environment is considered stressful is known as the process of cognitive appraisal. Cognitive appraisal consists of primary and secondary appraisal. Primary appraisal refers to the process of evaluating the degree of threat the situation presents. Primary appraisals typically categorise situations as irrelevant, benign or stressful. A situation that is considered irrelevant is one that has no implications for a person's wellbeing. A situation that is benign is thought to have positive implications

for a person's wellbeing. A stressful situation is one that consists of threat, challenge or harm/loss (Lazarus & Folkman, 1984).

A stressful situation involving threat is one that the person perceives to be highly threatening and exceeding his/her personal resources. A challenge is a stressful situation that is perceived as threatening but not exceeding personal resources. A loss is a situation in which a valued thing (for example, a possession, a personal attribute or feeling) or person is lost. These categories are not mutually exclusive or static. Stressful situations may involve elements of all of the categories or may change categories according to the changes in appraisal as the situation unfolds (Lazarus & Folkman, 1984).

For example, a woman receiving a diagnosis of EBC may perceive the diagnosis to be fatal and therefore consider her situation as highly threatening and exceeding her resources. Another woman undergoing adjuvant chemotherapy for EBC may perceive the treatment to be taxing but not exceeding her resources and therefore consider her situation as a challenge. Another woman undergoing bilateral mastectomy may perceive the treatment to be damaging to her self-esteem, body image, and sexuality. Therefore, she may consider her situation as a loss.

Secondary appraisal refers to the evaluation of ways in which the situation can be dealt with. It involves consideration of the coping options available, the expected success of the coping options, and the ability of the person to carry out the coping options effectively (Lazarus & Folkman, 1984). For example, consider a woman with EBC who is suffering from debilitating nausea and vomiting as a result of chemotherapy treatment. Her secondary appraisal might include considering all of the things that she could do to reduce the nausea and vomiting (for example, taking anti-emetic medication) and then considering the success of these options (whether the anti-emetic medication had worked in the past) and her ability to carry out the option (whether she has any medication left).

Cognitive-transactional theory of stress also states that the process of appraisal is influenced by a range of personal and situational factors. Personal factors include commitments (for example values, goals and desires) and beliefs (existing ideas about

the self and world). Situational factors include the properties of situations that contribute to their perception of being stressful (for example, novelty, predictability, uncertainty, ambiguity, and the timing of stressful situations). The theory considers these factors to be interdependent in their influence on appraisal (Lazarus & Folkman, 1984).

3.1.4 Summary

The evolution of stress theories has increasingly emphasised the importance of both the person and the environment and the appraisal of this relationship in the experience of stress. While early theories considered stress to be an objective, external demand placed on a person, it is now widely considered to be a situation that is perceived to be threatening by the person. This appraisal then results in the experience of a range of psychological and physical outcomes indicative of stress. The level of stress experienced will vary as a function of this relationship such that any changes in the way in which the threat is perceived will alter the stress experienced (Cannon, 1915; Lazarus & Folkman, 1984; Selye, 1956, 1976).

3.2 Approaches to Coping

The significant detrimental effects of stress on physiological and psychological wellbeing highlight the importance of effectively dealing with that stress. This begs the question as to what can be done to mitigate the effects of stress. This question has captured the attention of many researchers and resulted in an extensive literature devoted to the theory and empirical findings of the concept of coping. At the fundamental level, coping may be conceived as any attempt aimed at mitigating the effects of a stressful situation (Stone et al., 1991; Stone, Helder, & Schneider, 1988). The sheer volume of literature serves to emphasise the critical role of coping in mediating the effects of stress on wellbeing (Endler & Parker, 1990).

Despite the attention accorded to coping theory and research, the range of coping responses and the way in which these mitigate the effects of stress is still poorly understood. Early theories of coping followed on from Cannon (1915, 1929) and Selye's (1956, 1976) theories of stress and focused on the behavioural responses of animals to stressful environmental conditions (Koolhaas et al., 1999; Lazarus & Folkman, 1984). Although they provided important empirical confirmation of the

theories, they were criticised for failing to capture the complexity of both behavioural and cognitive coping responses employed by humans (Lazarus & Folkman, 1984). Later theories attempted to do so, but from very different perspectives. Few attempts have been made to unite the many diverse theories in an effort to gain an overall understanding of the nature of coping (Stone et al., 1988). The following section will outline the three main approaches to coping: the trait, strategy and disposition approaches.

3.3 Trait Approach to Coping

The trait approach originated in Freud's (Freud, 1938) psychoanalytic theories and received much attention in the 1960s to present day. He stated that people sometimes experience thoughts, impulses and desires that are considered unacceptable and lead to the experience of anxiety. In order to resolve the discrepancy and in turn reduce anxiety, a series of defense mechanisms are activated. These defenses ensure the thoughts, impulses, and desires are kept out of awareness but that gratification is achieved by expressing the desire in some alternative, acceptable manner (referred to as a symptom). The defenses are not observable but are instead inferred from the resulting, observable symptoms (Cramer, 1991, 1998; Davidson & MacGregor, 1998; Perry & Ianni, 1998).

Defenses are defined as unconscious, unintentional, automatically activated cognitive operations in which perception of the stressful event or state is altered in order to reduce anxiety. They are distinguishable from defensive behaviour which is the observable behaviour that operates consciously to decrease threat. In theory, people can be aware of their habitual behaviour but still remain unaware of both the perception of the stressful event or state and the activation of the defense mechanism (Cramer, 1991, 1998; Davidson & MacGregor, 1998; Krohne, 1993; Weinberger, 1995).

Some commonly discussed examples of defense mechanisms include repression, devaluation, idealisation, intellectualisation, denial, and projection. Repression is when disturbing thoughts, feelings or desires are barred from awareness. Devaluation is when the negative qualities of others are exaggerated while idealisation is when the positive qualities of others are exaggerated. Intellectualisation is when a person excessively uses abstract, rational thinking to control or minimise painful feelings. Denial is when a

person refuses to acknowledge painful aspects of reality (American Psychiatric Association, 1994).

Several examples of these defenses can be provided when considering the case of a woman undergoing chemotherapy for EBC. After undergoing the first chemotherapy treatment, the woman experiences nausea and vomiting, alopecia, and fatigue. As a result, she is dreading her next treatment. She says that although she cannot engage in any of her hobbies, these are not enjoyable anyway (intellectualisation). While she knows she may experience alopecia, her hair is not falling out (denial). She reports to her husband that she cannot remember her next treatment appointment (repression).

Despite accusations to the contrary, defenses are thought to be part of normal personality functioning and only become associated with psychopathology when they are used excessively, rigidly, and/or inappropriately according to developmental stage (Cramer, 1991; Davidson & MacGregor, 1998). As such, all people display a pattern of defenses which are thought to be based on early childhood experiences of anxiety in response to stressful external or internal states (Cramer, 1991).

As a part of personality, defenses are considered to be relatively stable, enduring, and predictable ways of coping with stressful states (Cramer, 1991; Krohne, 1993; Weinberger, 1995). It is thought that each defense is unidimensional and therefore people are classified on a continuum of each defense according to the extent to which they employ the defense (Lazarus & Folkman, 1984). At present, limited empirical research has been conducted to validate the stability of defenses (Cramer, 1998) with some maintaining that their employment depends on the situation at hand (Davidson & MacGregor, 1998). However, little research has investigated the person and content factors that might affect such employment (Miller, 1990; Wilson, 1984).

There is little consistency in the identification and description of the defense mechanisms. Freud (1938) did not clearly distinguish between the defenses referring instead to one mechanism of repression. It was not until later that efforts were made to delineate the various defenses. A lack of consistency and clarity regarding the number and nature of defenses remains (Cramer, 1998; Davidson & MacGregor, 1998; Watson, Pettingale, & Greer, 1984).

Within each taxonomy of defenses, there is a hierarchy based on psychological maturity. Defenses are thought to reflect the level of personality functioning with higher levels considered more mature and complex and lower levels more immature and primitive. Typically, denial is considered an immature defense, projection is considered of intermediate maturity, and identification is a mature defense. The range of possible defenses and their effectiveness are thought to vary as a function of development but again, limited empirical research has been conducted to investigate this idea (Cramer, 1998, 1999).

Just as the type and nature of defenses are disputed, so too are the organization of defenses into hierarchies. To date, many hierarchies have been proposed (Cramer, 1991; Haan, 1977; Vaillant, 1977), but few have received empirical investigation. Generally, the more mature the defense, the more effective method of coping it is considered to be. More mature defenses are thought to be better able to reduce anxiety, restore self-esteem and preserve the integration of the self. That is, the trait approach equates effective coping with adaptational success (Lazarus & Folkman, 1984). Although this appears to imply that all defenses are adaptive, this is not the intention (Davidson & MacGregor, 1998). Some believe that the focus on adaptational success is too limited a definition of coping effectiveness for two reasons: not all stressful situations can be adapted to and mastered, and it fails to acknowledge other important outcomes of coping such as problem-solving (Lazarus & Folkman, 1984). Some ways of coping considered immature (for example denial and avoidance) have been shown to be effective in terms of psychological outcomes (Auerbach, 1989).

3.3.1 Measurement of Trait Approach

The unconscious nature of defenses and the existence of numerous and diverse definitions have seen clinicians and researchers interpret and conceptualise defenses in different ways. This has led to the development of several methods of measurement, none of which have been universally accepted and utilised by researchers (Cramer, 1998; Lazarus & Folkman, 1984; Weinberger, 1995). The forms of measurement consist of unstructured interviews, projective tests, and self-report inventories.

Following from Freud's (1938) work, initial methods of assessing defenses involved unstructured interviews by a trained clinician. The information collected is used to determine which defenses are routinely employed by the respondent. The identification of defenses from the information collected may be determined via clinician intuition or through the use of one of the many formal, published coding systems. However, concern exists regarding the lack of standardised conditions under which information is elicited in unstructured interviews.

In an attempt to overcome this issue, projective tests have been employed. Projective tests involve the presentation of a series of cards consisting of pictures of ambiguous stimuli that the respondent is instructed to interpret. It is thought that interpretation of the stimuli requires respondents to draw on their own drives, emotions, and conflicts, all of which reveal their personality. The two most commonly employed tests are the Rorschach Test (Rorschach, 1941) and the Thematic Apperception Test (Murray, 1943).

Coding systems typically employed for interviews and projective tests aim to provide a list of responses that have been reported by large samples, indicate whether responses are commonly reported, and the degree to which they reflect defenses. Coding systems typically involve written descriptions of defenses which vary from the provision of a simple definition to the provision of a definition as well as descriptions of the functions, similarities and differences of defenses, and ways of differentiating between them (Perry & Ianni, 1998). Although many systems have been proposed and used, none has received wide acknowledgement and acceptance.

Once defenses have been identified via the interview or projective test, the coding systems then record defenses in two ways: on a dichotomous scale indicating presence or absence, or on a Likert scale indicating the extent to which the defense is used. Scores may be summed to give a score of individual defenses or global defensiveness which may be compared to population norms, if available, or scores of individual defenses may be ranked in order of the extent to which they are used in comparison to each other (known as the Q-Sort technique) (Perry & Ianni, 1998).

The use of these tests of trait coping ensures that all respondents are presented with the same stimuli and the use of defenses is again determined via a coding system. The

open-ended response format of unstructured interviews and projective tests allows the collection of detailed information. This, together with the fact that the information may, in part, be collected and interpreted by clinicians experienced in the theory and use of defenses, may contribute to the validity of these forms of assessment. The use of objective and standardised coding systems are thought to enhance the reliability of the forms of assessments (Perry & Ianni, 1998).

Despite attempts to ensure the reliable and valid assessment of defenses, several concerns have been raised regarding the use of clinical interviews and projective tests. As mentioned, the lack of standardised stimuli to which responses are elicited in unstructured interviews has been criticised. While the use of standardised stimuli in projective tests have been suggested to overcome this issue, the extent to which the stimuli are interpreted similarly across respondents is still largely unknown (Davidson & MacGregor, 1998). Neither forms of assessment necessarily involve the use of stimuli that require respondents to comment on their responses to stressful situations, which may affect validity of interpretations about the use of defenses (Stone et al., 1991; Stone et al., 1988).

It appears that few coding systems have been standardised on large samples representative of the general population and/or specific populations (Davidson & MacGregor, 1998; Perry & Ianni, 1998). As a result, it is unknown whether coding systems accurately categorises responses into defenses. Although not a criticism, the fact that the delivery and interpretation of interviews and projective tests requires significant training on the part of clinicians and/or researchers, making them time- and labour-intensive and expensive, makes their use in research, especially with large samples, potentially prohibitive.

In response to the increasing emphasis on the importance of quantitative measurement from some researchers, self-report measures designed to assess individual defenses and/or global defensiveness have been developed. They consist of written stimuli to which a person responds by selecting one of several response options. Response options reflect the extent to which the individual defenses or overall use of defenses are employed. Like interviews and projective tests, some self-report measures do not refer

to stressful situations (Byrne, Golightly, & Sheffield, 1965; Millon, Green, & Meagher, 1982; Rohde, 1948).

The most commonly utilised self-report inventories include Byrne's Repression-Sensitization Scale (R-S scale) (Byrne et al., 1965), the Sentence-Completion Test (SCT) (Rohde, 1948) and the Millon Behavioural Health Inventory (MBHI) (Millon et al., 1982). The R-S scale measures the defense of repression by asking people to indicate the extent to which they avoid information about stressful situations or states. The SCT measures repression by asking respondents to indicate their desire to avoid or block out sentences describing threatening emotions such as hate, fear, sexual desire and so on. The MBHI assesses several personality dimensions thought to be relevant to wellbeing and decision-making in the medical setting, including three repressive coping styles of introversive, cooperative and respectful.

3.3.2 Advantages and Disadvantages of Trait Coping Measures

There are several clear advantages to using self-report inventories for measuring defenses. Like projective tests, the stimuli are objective and the stimuli and response scales are standardised across respondents. Self-report measures require no interpretation of responses as response options and scale scores are standardised. Unlike interviews and projective tests, self-report measures are comparatively inexpensive, easy to administer and score, brief, contain easily understandable instructions, and require little training of examiners (Groth-Marnat, 1999).

Despite these advantages, self-report measures have also attracted criticism. They are considered to lack construct validity. Theoretically, Cramer (Cramer, 1998) asserts that asking respondents to report on their use of defenses means they are reporting on conscious, not unconscious, cognitive acts. Stone and colleagues (Stone et al., 1991; Stone et al., 1988) believe that existing methodology are not able to adequately assess unconscious coping. However, Cramer does concede that respondents may be able to report on the conscious symptoms of defenses, despite a lack of awareness of the meaning of the behaviours from which defenses may be inferred (Cramer, 1998). Even so, reports of this behaviour may be affected by social desirability. Methodologically, considerable associations have been shown between self-report scores and scores on

measures of similar, though theoretically distinct, constructs such as social desirability and trait anxiety (Weinberger, 1995).

It is thought that the scores obtained on self-report measures focusing on the lower and upper scores on defenses, such as the R-S scale, have been used inappropriately. Researchers have routinely ignored middle scores when making claims about the linearity or otherwise of defense scores and outcomes, which may be misleading (Wilson, 1984). It is also unknown whether scores claiming to measure the extent to which defenses are employed are valid, as few comparisons have been made with clinical judgments of defense use (Davidson & MacGregor, 1998). All of these measurement difficulties, coupled with the lack of theoretical consistency of defenses, have meant that the use of the trait approach has stalled in recent years.

3.4 Strategy Approach to Coping

The strategy approach has attracted significant attention from theorists and researchers alike. Many models taking the strategy approach have been remarkably consistent in their definition and conceptualisation of coping and subsequent operationalisations of strategies have been amenable to empirical investigation. The strategy approach grew out of the transaction theory of stress to provide a very different perspective on the conceptualisation of coping from the trait approach. The approach defines coping as the dynamic process in which cognitive and/or behavioural efforts (or strategies) are employed in order to deal with the demands of a stressful situation that challenges a person's resources (Lazarus & Folkman, 1984).

This definition makes several specifications about coping that distinguish the strategy approach from the trait approach. The definition emphasises that coping is a process in which efforts aimed at dealing with the stressful situation change continually in response to changes in the way the relationship between the person and the stressful situation is appraised. Coping only refers to effortful and conscious acts that deal with a situation, rather than automatic or unconscious acts that may be adaptive in stressful situations. The approach is only concerned with the actual way in which people cope with a given situation, not the way in which most situations are coped (Lazarus & Folkman, 1984).

As indicated by the transactional theory of stress, coping results from an appraisal process in which people assess the nature and severity of the stressful situation and their ability to effectively deal with the situation. Appraisal of the stressful situation is thought to continually change, depending on changes to the situation or to the effectiveness of coping strategies employed. As such, as appraisals change, so too do the coping strategies employed and their effectiveness. Any consistencies in coping strategies used over time are determined empirically by assessing coping across a number of stressful situations, unlike the trait approach which views defense use as inherently stable (Stone et al., 1991).

Although the strategy approach does view coping largely as context-dependent, it does consider other person-specific factors to have an influence on the strategies employed and their effectiveness. As yet, the identification of these specific factors and the way in which they affect coping are not widely articulated. It is clear, however, that few strategy theorists and researchers consider defenses to be one such person-specific factor. Alternatively, several trait theorists and researchers acknowledge and distinguish between defenses and coping strategies, and their contributions to managing stressful situations (Cramer, 1998).

Attempts have been made to identify all possible coping strategies that may be employed in stressful situations and to organise these strategies into broader categories of coping. The most commonly employed categories are problem-focused and emotion-focused coping. Problem-focused coping refers to efforts aimed at directly managing the stressful situation. Problem-focused coping is more likely when the situation is appraised as controllable. Examples of these strategies include defining the problem, generating possible solutions, assessing the costs and benefits of the solutions, decision making regarding the solution to be used and executing the solution (Lazarus & Folkman, 1984).

Problem-focused coping may be aimed at the environment or the self. For example, problem-focused coping strategies aimed at the environment might include reducing barriers to managing the problem and engaging the available material resources. Problem-focused coping aimed at the self might include developing new aspirations, finding alternative forms of gratification, and learning new skills. In the case of a

woman diagnosed with EBC, problem-focused coping strategies might include taking time off work in order to undergo and recover from treatment, reducing high-risk behaviours such as alcohol consumption, and taking medication to relieve the side effects of treatment (Lazarus & Folkman, 1984).

Emotion-focused coping refers to efforts to reduce distress, induce positive mental states and on some occasions, increase distress. Strategies aimed at increasing distress are less common but may be helpful in mobilising the person to employ problem-focused coping strategies. In contrast to the use of problem-focused coping, emotion-focused coping is more likely when the situation is appraised as uncontrollable. Examples of the strategies aimed at reducing distress include avoidance, distraction, minimisation, selective attention, making positive comparisons, finding benefits in the situation and seeking social support. For a woman diagnosed with EBC, emotion-focused coping strategies might include avoiding thinking about the prognosis of the diagnosis, comparing oneself favourably to others with more serious cancer diagnoses, distracting oneself from thoughts of the disease by engaging in unrelated activities (such as going to the movies), and seeking reassurance from family and friends (Lazarus & Folkman, 1984).

More recently, arguments have been made for the inclusion of avoidance (Endler & Parker, 1990) and social support (Moos & Schaefer, 1993) as broad categories in their own right. The use of problem- and emotion-focused coping categories has received criticism for prematurely oversimplifying the diversity of coping strategies that may exist (Stone et al., 1988). Clearly, empirical confirmation of these theoretical categories is needed (Krohne, 1993).

Despite consistency in the use of the few broad categories outlined, the individual strategies classified in each have differed slightly, depending on the researchers' interpretation of the intention of the strategies. For example, seeking social support may be a way of gaining information about the situation or a way of venting distress and as such, may be considered a problem-focused or emotion-focused strategy respectively. Seeking social support may be employed for both purposes, signalling that strategies can have several simultaneous intentions. The categories of strategies are not mutually exclusive and can be employed at the same time. In some cases, different categories of

strategies may interact by facilitating or impeding each other. Stressful situations may have various effects on a person and their circumstances, any of which are effectively dealt with using different types of strategies (Stone et al., 1991).

The strategy approach views the effectiveness of coping as independent of actual outcomes. Unlike the trait approach, the strategy approach does not consider any coping strategy a priori to be inherently effective or ineffective. Rather, effectiveness depends on the fit between the strategies employed, the other existing person and situational factors, and the person's desired outcomes (Lazarus & Folkman, 1984). The many contradictory findings in the literature investigating the outcomes of coping strategies may reflect the idea that the effectiveness of strategies depends on many factors (Oakland & Ostell, 1996). While this undoubtedly results in a richness of detail regarding the people and situations which demonstrate effective coping, it has not provided information about the general patterns of association between coping strategies and outcomes. Therefore the approach is useful when considering specific people, situation and short-term outcomes but not when considering general outcomes in the longer term (Lazarus & Folkman, 1984).

3.4.1 Measurement of Strategy Approach

The strategy approach has consistently involved one form of measurement, that is, multidimensional self-report inventories. Measures of coping strategies typically instruct respondents to recall a past stressful situation and indicate the extent to which they employed the listed cognitive and behavioural strategies on a Likert scale. The first of these was the Ways of Coping Checklist (WCC) by Lazarus and Folkman (Folkman & Lazarus, 1980). Subsequent inventories appear to be mostly modifications of the WCC (Oakland & Ostell, 1996) and include the Ways of Coping Questionnaire (WCQ) (Folkman & Lazarus, 1988), the Coping Orientations to Problems Experienced (COPE) (Carver, 1989), the Multidimensional Coping Inventory (MCI) (Moos & Schaefer, 1993), and the Coping Inventory for Stressful Situations (CISS) (Endler & Parker, 1990).

More recently, however, scales originally designed to measure adjustment have been employed for the express purpose of assessing coping strategy use. The most common example is the use of the Mental Adjustment to Cancer (MAC) scale (Watson, Meyer,

Thomson, & Osofsky, 1998). Where coping refers to voluntary cognitive and behavioural efforts to deal with stressful situations, adjustment refers to both voluntary and involuntary responses to situations (Nordin, Berglund, Terje, & Glimelius, 1999).

3.4.2 Advantages and Disadvantages Strategy Coping Measures

Advantages of these measures are their ease and low cost in administration and scoring, and the inclusion of a large number of coping strategies. This means they can be administered to a large number of participants and a comprehensive understanding of the coping strategies employed is possible (Oakland & Ostell, 1996). As such, these measures have been hugely popular in the literature with many studies investigating coping via this approach.

Even so, the measures have attracted considerable criticism. The lack of theoretical reasoning regarding the number and type of coping strategies that exist mean that measures appear to include a random sample of strategies that are grouped into broad categories empirically. In some cases, items within one broad category are inversely correlated so calculation of an overall score can be misleading. For example, emotion-focused items of approach and avoidance are inversely correlated so aggregation may lead to a loss of information about the extent to which emotion-focused strategies are employed (Stone et al., 1991; Stone et al., 1988). As Folkman (1992) states, “the problem of finding the critical number of types of strategies to evaluate and how to summarise coping patterns awaits a creative solution” (p. 36).

The reliance on retrospective recall may be subject to bias and therefore the accuracy of responses of questionable validity. Participants may recall the coping strategies they used most frequently, either first or last, at the most intense period of a situation, generally across a range of situations, or that were the most effective (Ptacek, Smith, Espe, & Raffety, 1994). Empirical research has indicated that people interpret the descriptions of coping strategies in measures differently and are often able to provide several interpretations of a strategy. Given that measures only assign each strategy one meaning, interpretation differences could lead to low internal consistency of items (Stone et al., 1991).

Differences in the coping strategies employed may not reflect different preferences for or mastery of particular strategies but rather a difference in the nature of the stressful situation and its appraisal. By instructing respondents to recall a stressful situation without detailing the situation makes it impossible to know whether its nature and appraisal are equivalent between participants. Few, if any, efforts have been made to determine and assess the qualities of the stressful situation and appraisal processes that may affect the coping strategies employed (Stone et al., 1991; Stone et al., 1988).

Moreover, determining the strategies used to deal with particular aspects of the stressful situation at particular times is rarely investigated, despite the importance of temporality as emphasised by the approach. Failure to do so means that the comparison of coping and its effectiveness between participants is misleading (Auerbach, 1989; Stone et al., 1991; Stone et al., 1988). A recent attempt to shed light on this issue consisted of daily ratings of coping strategies used (Wasteson, Nordin, Hoffman, Glimelius, & Sjoeden, 2002), although the choice of daily intervals in ratings was arbitrary and the different stages may occur at other intervals so despite significant effort on the part of respondents, the method may still fail to capture the complexity of coping.

People have also been shown to interpret the response scale differently as well. These differences occur in four main ways: the frequency with which the strategy was used, the duration of each strategy, the amount of effort required in executing the strategy, and the usefulness of the strategy. The last of which, usefulness, contradicts the strategy approach in that it equates coping and success (Stone et al., 1991). Asking respondents to indicate the extent to which they employed a particular coping strategy and correlating responses with outcome variables has several problems. The response does not include provision for the competency with which the strategy is employed, the adequacy of resources available to deploy the strategies, and the effect of each deployment of a strategy as a function of interaction with other situational and personal factors (Oakland & Ostell, 1996).

3.5. Dispositional Approach to Coping

The dispositional approach aims to determine the patterns of strategies a person habitually employs across a range of stressful situations. These overall patterns are referred to as coping styles or modes (Agre et al., 2003; Krohne, 1989; McCrae, 1992;

Miller, 1990). Theorists of the dispositional approach do not consider dispositional coping to be mutually exclusive from the trait and strategy approaches to coping (Roth & Cohen, 1986). Instead, the approaches are thought to focus on different levels of the coping process. Coping traits refer to the rigid coping efforts employed in all situations, coping styles are preferred coping efforts that are employed in most situations, and coping strategies are employed variably in a range of situations, depending on situational and personal factors (Compas, Malcarne, & Banez, 1992; Krohne, 1993).

As stated, the strategy approach considers that some person factors may influence the strategies employed in situations and coping styles may be one such factor (Lazarus & Folkman, 1984). Some empirical evidence has found there to be a moderate association between coping styles and the coping strategies employed in stressful situations (Brown & Bedi, 2001) although results have been mixed and debate continues regarding the level of expected correspondence between the two (Carver, 1989; Myers & Derakshan, 2000). It has been suggested that an understanding of dispositional coping styles may provide a way of systematising research on coping while preserving some of the complexity of the process (Lazarus & Folkman, 1984).

Like the strategy approach, the dispositional approach does not view coping styles as inherently effective or ineffective but instead relies on their interaction with personal and situational factors. That is, the approach has focused on determining the circumstances under which individual coping styles are effective (Krohne, 1993; Miller, 1990; Miller, 1996). Empirical evidence supports the relationships between coping styles and the other theoretically distinct personal and situational factors. For example, it has been shown that the situational factors of controllability and stressfulness of the situation (Valentiner, Holahan, & Moos, 1994; van Zuuren, de Groot, Mulder, & Muris, 1996) and the person factors of age and gender (van Zuuren et al., 1996; van Zuuren & Wolfs, 1991) influence the coping styles reported.

Coping styles have invariably focused on the separate dimensions of information seeking and information avoidance (Ben-Zur, 2002; Krohne, 1993; Miller, 1979a; Roth & Cohen, 1986). Information seeking describes the cognitive and behavioural efforts to obtain information about the stressful situation whereas information avoidance describes efforts to distract or escape this information. Well-known theories are

Krohne's (1989) theory of vigilance and avoidance, and Miller's (1979a) theory of monitoring and blunting, with vigilance and monitoring referring to information seeking and blunting referring to avoidance. The number of theories and their overlap in the conceptualisation of information seeking and avoidance is thought to reflect the robustness of these coping constructs (Miller, 1996).

3.5.1 Measurement of Dispositional Approach

Measures of dispositional coping typically consist of the presentation of several stressful situations, each of which is followed by possible strategies for coping with the situation. Participants are asked to indicate the extent to which they believe they would utilise these strategies. The use of several situations that vary on dimensions thought to influence coping, such as the degree of controllability, predictability and stressfulness, is used to ensure the generalised pattern of coping is revealed. Responses to each strategy are aggregated to show the overall coping style (Krohne, 1989). The most common measure includes the Miller Behavioral Style Scale (MBSS) (Miller, 1987), followed by the Threatening Medical Situations Inventory (TMSI) (van Zuuren et al., 1996) and the Mainz Coping Inventory (MCI) (Krohne, 1989).

3.5.2 Advantages and Disadvantages of Dispositional Coping Measures

Originally, response scales were a dichotomous true/false format but recent versions consist of Likert scales, which have demonstrated higher internal reliability (Muris, Van Zuuren, Merckelbach, Stoffels, & et al., 1994e; van Zuuren & Wolfs, 1991). Scores of each coping style were commonly collapsed across styles and median split procedures were employed to determine those who utilise the combined coping style to a greater or lesser extent. Concerns regarding the loss of information entailed in these procedures have resulted in the use of individual scores for each coping style measured and investigation of scores as a continuous variable (Bijttebier, Vertommen, & Vander Steene, 2001; Miller, 1990; Muris et al., 1994e). At times, researchers have utilised only a selection of stressful situations in a measure in order to create a short-form version (Miro, 1997). This contradicts the purpose of providing a range of stressful situations that differ on important dimensions (van Zuuren, de Jongh, Beekers, & Swinkels, 1999) and has received limited empirical support (Miro, 1997).

The limited research available indicates there is a moderate correspondence between the coping styles predicted in response to hypothetical stressful situations and those actually used (Miller, 1987; Miro, 1997; van Zuuren, 1994) whilst others have shown little or no association (Muris et al., 1994e; van Zuuren & Muris, 1993). Empirical evidence from a limited number of studies indicates that the stressful situations described may be difficult to imagine (Muris, van Zuuren, De Jong, De Beurs, & et al., 1994c; Steptoe, 1989). At times, it has been reported that coping styles are poorer predictors of outcomes than strategies and therefore, their usefulness has been questioned. However, Krohne (Krohne, 1993) believes that poor construct validity of some scales may account for such results but that trying to predict outcomes from coping efforts occurring immediately preceding an event is of little benefit as the aim of the dispositional approach is to determine likely outcomes from habitual coping responses, rather than those employed in a specific situation which can be taxing to determine on each occasion.

3.6 Summary of the Approaches to Coping

Coping aims to minimise the effects of stress on physical and psychological well-being. Broadly speaking, coping can be defined as any attempt to mitigate the stressfulness of a situation and restore wellbeing. Coping can be considered from several approaches: coping may consist of unconscious, defensive cognitive acts (known as the trait approach), conscious behavioural and cognitive efforts (the strategy approach), or habitual patterns of behavioural and cognitive efforts (the dispositional approach). On the whole, the approaches are not considered to be mutually exclusive but rather represent the various levels at which coping can be considered.

Despite the advantages of examining coping from a number of approaches, all have varying strengths and weaknesses. The trait approach consists of diverse theories about potentially powerful yet unconscious coping mechanisms aimed at blocking the experience of stress. The definitions of coping defenses are clear and consistent across theories but the conceptualisations of individual defenses vary considerably, are difficult to operationalise and measure, and therefore investigate empirically (Davidson & MacGregor, 1998; Perry & Ianni, 1998).

The strategy approach involves numerous consistent theories of the individual coping strategies employed in specific stressful situations. Benefits of the approach consist of the clear definition of coping, coping strategies are easy to operationalise, measure, and empirically investigate. However, the conceptualisations of coping strategies are sometimes contradictory, unclear, and incomprehensive and such fine-grained analysis of coping has generally failed in its efforts to provide an understanding of complexity of coping and its outcomes (Folkman, 1992; Stone et al., 1991; Stone et al., 1988).

The dispositional approach has many of the benefits of the strategy approach; it consists of clear though narrow definitions of coping styles, the coping styles are easy to operationalise, measure and empirically investigate, and it also acknowledges the role of other personal and situational factors in coping. Most importantly, it has the potential to provide an overall understanding of the outcomes of coping (Krohne, 1993).

3.7 Conclusions

Consideration of the theories of stress and coping are clearly important in understanding the experience of stressful situations. The theories outline the way in which people come to experience stress and the many ways in which they may cope with stressful situations. This serves to highlight the numerous possible avenues for empirical investigation of stressful situations. In so doing, variations in the experience of stressful situations in terms of physical and psychological wellbeing may be better understood. Efforts may be made to utilise this understanding to develop and implement interventions aimed at reducing maladaptive forms of coping and enhancing adaptive forms, thereby ensuring improved physical and psychological wellbeing. As illustrated, the coping approaches have the potential to identify some of the ways in which women cope with the diagnosis and treatment of EBC. Therefore, their application to the understanding of the EBC journey is critical.

CHAPTER FOUR

Coping with the Clinical Experience of Breast Cancer

The application of the coping approaches to the experience of breast cancer is prolific. Researchers and clinicians alike are excited by the potential for the coping approaches to expose the way in which the breast cancer journey is experienced and identify opportunities for intervention. All coping approaches have been utilised in an effort to fully understand the range of coping and outcomes possible across the entire breast cancer experience. It will become evident that many studies have utilised the coping strategies approach and have examined the experience of breast cancer rather than EBC. The use of the strategies approach is no doubt because the approach is amenable to empirical investigation and samples of breast cancer are easier to recruit than those with the more specific diagnosis of EBC. The following section will outline the empirical literature in four main areas: the aetiology and progression, diagnosis, and treatment of breast cancer. Attempts have been made to include research including all coping approaches and those examining women with EBC.

4.1 Coping and the Aetiology of Breast Cancer

Interest in the role of coping in the aetiology and progression of breast cancer commenced in the 1960s, a time in which rates of breast cancer were noticeably increasing in the Western world (Key et al., 2001; Veronesi et al., 2005). This interest has continued in recent years, in part due to the inability to explain the medical reason as to why and how cancer develops and progresses. As a result, there is considerable empirical literature investigating the topic, much of which varies greatly in terms of the quality of research designs (Bleiker & van der Ploeg, 1999; Bryant-Lukosius, 2003; Butow et al., 2000a; De Boer, Ryckman, Pruyn, & Van den Borne, 1999; Garssen, 2004; Gerits, 2000; Petticrew, Bell, & Hunter, 2002). It is a topic that has captured the attention of researchers and clinicians as well as the general public. The latter is illustrated by the plethora of media reports, popular books, patient workshops, and so on that discuss the role of coping in the cancer experience (Satterlund et al., 2003).

4.1.1 Retrospective Studies

Studies investigating the topic can be classified into three categories of research design: retrospective, quasi-prospective, and prospective designs. In the retrospective design, patients diagnosed with breast cancer are analysed retrospectively on coping and compared with control groups consisting of patients with other medical conditions (most commonly those with benign breast disease) and/or healthy random samples of the general population (Bleiker & van der Ploeg, 1999). Several retrospective studies have found significant differences in coping used by cancer patients compared to controls.

In one of the first retrospective studies, around 70 breast cancer patients were compared to controls consisting of a sample of women with a medical condition (cystic fibrosis) and a population-based sample. The results suggested that cancer patients used coping strategies that involved less assertiveness and expression of anger than both control groups (Jansen & Muenz, 1984). This findings was further confirmed in smaller studies by Watson and colleagues (Watson et al., 1984), and Goldstein and Antoni (Goldstein & Antoni, 1989) involving around 30 breast cancer patients and population-based control groups. Both found cancer patients to have more repressive coping than controls. The former also found cancer patients engaged in more coping involving the suppression of anger than controls.

While these results appear to be similar, it is difficult to distinguish between the coping described as emotional suppression versus repression, as the researchers provided few descriptions and examples of the forms of coping measured. Traditionally, however, suppression involves the conscious avoidance of emotion while repression involves the unconscious avoidance of emotion despite significant physiological arousal. In other words, suppressors know they are experiencing intense emotions but make efforts to actively inhibit them while repressors are unaware that they are experiencing such emotions (Giese-Davis & Spiegel, 2002).

Concerns exist regarding the validity of findings from studies using the retrospective design. The appropriateness of the control groups has attracted significant debate. Some believe that the use of women with benign breast disease as controls is superior to population-based controls because the former have similar levels of concern prior to

diagnosis as those who are diagnosed with cancer. However, others argue that these women are also at an increased risk of the disease. There are several additional concerns about retrospective designs. There is the possibility that the disease influences personality and therefore affects coping efforts. Patients' knowledge of their diagnosis may affect the way they recall information on coping and other psychosocial variables assessed. Lastly, the cross-sectional design makes it difficult to determine causality (Bleiker & van der Ploeg, 1999).

4.1.2 Quasi-Prospective Studies

The quasi-prospective design consists of examining the coping efforts of patients with suspicious symptoms prior to diagnosis and comparing those who go on to receive a diagnosis of breast cancer to those who do not. It is thought that by recruiting participants with suspicious symptoms, all have equal levels of distress and fear of cancer prior to diagnosis. One study investigated coping in more than 2000 women attending out-patient health clinics or breast screening centres, over 75% of whom had detected breast symptoms indicative of breast cancer. Over 170 of these women were subsequently diagnosed with breast cancer. The results showed that those diagnosed with cancer used more coping consisting of denial and suppression of anger than those without the disease (Cooper & Faragher, 1993).

Similarly, suppression of anger was also reported in a sample of 160 women, 69 of whom were diagnosed with breast cancer and the remaining with benign breast disease (Greer & Morris, 1975; Greer & Morris, 1978). Although, subsequent re-analysis that accounted for risk factors of menopausal status and age revealed that cancer patients were more likely to suppress all emotions, not just anger (Bleiker & van der Ploeg, 1999). Additional studies with smaller samples of more than 60 women reported more suppression of anger (Morris, Greer, Pettingale, & Watson, 1981), and emotions in general in those receiving a diagnosis of breast cancer than with benign breast disease (Wirsching, Hoffmann, Stierlin, Weber, & Wirsching, 1985).

Similarly, a study examining more than 800 women undergoing mammography revealed that the 20 women diagnosed with breast cancer demonstrated more coping aimed at emotional control than those with benign breast disease and healthy women (Fox, Harper, Hyner, & Lyle, 1994), although a poor response rate may indicate a

selection bias (Butow et al., 2000b). One study aimed to investigate the role of the coping efforts of problem-focused and emotion-focused engagement and disengagement. Of almost 200 women recalled following a suspicious mammography screening or breast biopsy, more than 100 were diagnosed with breast cancer. The results of the study revealed that those diagnosed with breast cancer had comparable coping efforts as controls. However, women diagnosed with breast cancer that had experienced one or more severe life events in the past five years were more likely to use problem-focused engagement coping (Chen et al., 1995).

On the other hand, some large-scale studies also revealed no difference in coping for women receiving a diagnosis of breast cancer and those with benign breast disease or healthy controls. Price and colleagues (Price et al., 2001) investigated more than 2000 women recalled following a routine mammography in a breast-screening program. They found equivalent use of defenses and strategies of emotional expression and control in the almost 300 women who went on to receive a diagnosis of the disease and those that did not.

An earlier study of more than 1000 women undergoing clinical examination and mammography assessed the coping efforts of maladaptive, denial/avoidance, seeking social support and venting. The results revealed equivalent coping for the almost 80 women with breast cancer and those without (Edwards, Cooper, Pearl, de Paredes, & et al., 1990). A smaller study of almost 40 women with breast cancer and 80 with benign breast disease undergoing breast biopsy investigated the coping strategies of cognitive avoidance, behavioural avoidance, positive focus, distancing and seeking social support. The results revealed those with breast cancer and those with benign breast disease reported comparative use of coping (Stanton & Snider, 1993).

A limitation of the quasi-prospective design is the possibility that patients may accurately infer their diagnosis from their symptoms or from interactions with medical professionals who know patients' diagnoses (Bleiker & van der Ploeg, 1999). Again, there is speculation that the disease may influence personality and consequently, coping efforts (Bleiker & van der Ploeg, 1999).

4.1.3 Prospective Studies

The prospective design involves following healthy populations over a period of time to allow the assessment of coping before disease becomes apparent and comparisons are made between those who develop breast cancer and those who do not. In a study of almost 9, 000 women, results indicated that repression was employed equally among those diagnosed with breast cancer and those that were not (Hahn & Petitti, 1988). Given that this was an earlier study, risk factors and medical variables were not widely established and as such, were not adequately accounted for. In a second study, almost 10, 000 women were followed up for over five years. The over 130 women diagnosed with breast cancer were found to use more minimisation of emotions coping than the remaining women (Bleiker, van der Ploeg, Hendriks, & Ader, 1996).

Although prospective designs are considered the most appropriate (Bleiker & van der Ploeg, 1999), the cost inherent in such a design has meant there are few such studies. Concerns also exist regarding the measurement of coping. Coping is often measured at study entry only, despite long follow-ups. This means that any changes in coping employed over time are not considered. This is particularly problematic when examining coping strategies, as they are theoretically expected to fluctuate considerably.

4.2 Coping and the Progression of Breast Cancer

4.2.1 Prospective Studies

More recent research has investigated the role of coping in the progression of breast cancer. Study designs have typically involved the assessment of coping within several months of diagnosis and overall and recurrence-free survival over a follow-up period of at least five years. Most studies accounted for a range of variables that have been implicated in increased survival, including demographic factors (for example, age), lifestyle factors (for example, alcohol consumption), disease characteristics (for example, disease stage, number of affected axillary nodes), and treatment factors (for example, type of surgery, whether received chemotherapy). Problems regarding the measurement of coping in prospective designs that were previously outlined are again a concern for the following studies.

The earliest studies of this kind were conducted by Greer and colleagues (Greer, Morris, & Pettingale, 1979; Greer, Morris, Pettingale, & Haybittle, 1990; Pettingale, 1984;

Pettingale, Morris, Greer, & Haybittle, 1985). They followed almost 70 EBC patients for 15 years. Patients completed measures of fighting spirit, stoic acceptance, helplessness/hopelessness, and denial at diagnosis. At 15 years, the results suggested that those using more denial and fighting spirit experienced increased overall and recurrence-free survival. Given that many of the factors implicated in survival were unknown at the time of study, these have not been adequately accounted for in the analyses (Gerits, 2000). The study has now been replicated by Giraldi and colleagues (Giraldi, Rodani, Cartei, & Grassi, 1997) with the appropriate consideration of these factors. Ninety-five patients with EBC were followed up for six years and were assessed on the similar coping strategies of fighting spirit, hopelessness, anxious preoccupation, and fatalism. The results showed that those using greater fighting spirit and less helplessness/hopelessness coping experienced greater overall survival.

Two remaining studies, however, failed to yield similar findings. A larger sample of almost 600 EBC patients was followed up for five years. The results suggested that increased overall survival was instead experienced by those using more helplessness/hopelessness coping (Watson, Haviland, Greer, Davidson, & Bliss, 1999). The second study with a smaller sample of more than 120 EBC patients followed patients for six to eight years. This time, the results indicated that those experiencing increased recurrence-free survival used more denial (Dean & Surtees, 1989).

A large-scale study of almost 850 breast cancer patients reported use of coping strategies including expression of emotions, wishful thinking, problem solving, positive reappraisal, avoidance, and escapism at diagnosis and were followed for up to nine years. The results indicated that greater expression of emotions was associated with increased overall survival (Reynolds et al., 2000). Similar results were reported in a smaller sample of around 130 EBC patients followed up for a shorter period of four years. Patients who reported more engagement in behaviours that expressed emotions experienced increased overall and recurrence-free survival (Hislop, Waxler, Coldman, Elwood, & Kan, 1987).

Two further studies reported an association between coping strategies and survival. Ninety-nine ABC patients were followed for two years after reporting the use of active, distractive, and avoidant coping. The results showed that these forms of coping were not

associated with survival but those who minimised the impact of cancer (referred to as a pattern of adjustment to cancer by the researchers) experienced increased overall survival (Brown, Butow, Culjak, Coates, & Dunn, 2000). In the second study, 27 women with a recurrence of breast cancer, 25 women in remission for two years, and 34 healthy controls were followed for almost two years. Participants reported on defensive and helplessness/hopelessness coping. The results showed that both strategies were associated with survival (Jensen, 1987).

Two further studies reported no significant association between coping and survival. The coping strategies of denial, passive coping, and isolation were assessed in more than 300 patients diagnosed with EBC who were then followed for 10 years. There was no association with survival and any of the coping strategies (Soler-Vila, Kasl, & Jones, 2003). In the second study, over 100 EBC patients were again followed-up for 10 years. Patients reported on their use of problem-solving, emotional control, self-encouragement, self-revalorisation, distraction, withdrawal, regression, distrust, pessimism, and depressive coping. There was no association between coping and survival (Buddeberg, Buddeberg-Fischer, & Schnyder, 1997; Buddeberg et al., 1996).

4.2.2 Meta-Analyses

Two recent meta-analyses have been conducted to determine the effect of coping on overall and recurrence-free survival in breast cancer, both of which have reported conflicting results. The first conducted by McKenna and colleagues (McKenna, Zevon, Corn, & Rounds, 1999) considered the results of 46 studies of participants with breast cancer, although some studies investigated constructs related to coping but not coping itself. The coping constructs investigated included conflict-avoidant coping, denial/repression and expression of anger. The results of the meta-analysis suggested a small but significant effect of denial/repression and to a lesser extent, conflict-avoidant coping on overall survival (McKenna et al., 1999).

A later meta-analysis conducted by Petticrew and colleagues (Petticrew et al., 2002) applied a more strict criteria to the studies reviewed, including only those that adjusted for potential confounders and that assessment of coping was carried out early on in the disease process. They considered 26 studies investigating overall survival and 11 studies investigating recurrence-free survival in participants with a range of cancers.

The forms of coping investigated included fighting spirit, helplessness/hopelessness, denial/avoidance, stoic acceptance/fatalism, anxious preoccupation, depressive coping, problem-solving coping, emotion-focused coping and emotional suppression.

The results of the review suggest that there was no demonstrated role of coping in survival and recurrence. The studies that reported a significant association between coping and overall survival and/or recurrence were small and/or methodologically weak studies and there were no consistent patterns in the forms of coping implicated in the significant associations. As Petticrew and colleagues (Petticrew et al., 2002) comment, "People with cancer should not feel pressured into adopting particular coping styles to improve survival or reduce the risk of recurrence" (p.1).

4.2.3 Intervention Studies

Several interventions have been designed to enhance survival following breast cancer diagnosis by encouraging the development and use of certain forms of coping. To date, interventions have varied significantly in terms of their intensity, the focus of intervention, and the point at which they are offered to patients. The most widely known intervention study is that of Spiegel and colleagues (Spiegel, Bloom, Kraemer, & Gottheil, 1989). They randomly assigned almost 90 patients with ABC to a supportive-expressive therapy aimed at enhancing emotional expression and a no intervention control group. Patients in the intervention group reported significantly improved mood and psychological adjustment around ten months post-entry compared to controls. Follow-up at ten years post-entry revealed a significant increase in overall survival in those undergoing the intervention compared to the control group, after controlling for a range of medical prognostic factors.

While impressive, these results have been challenged by Fox (1998) for two reasons. Fox compared the survival rates of the intervention and control groups to the rates of a matched control population. The results found that the intervention and control groups survived comparatively to the matched control population group. Fox also suggests that the median survival periods of the intervention and control groups are similar and therefore the difference between the two may be due to extreme values.

A replication of the effects of supportive-expressive intervention was conducted by Cunningham and colleagues (Cunningham et al., 1998). They delivered a similar supportive-expressive intervention that also included coping skills training and compared the intervention group to a control group that received written material used in the intervention. Sixty-six patients with ABC were randomly assigned to the groups. There were no significant effects of intervention on mood and psychological adjustment except for hopelessness which was reduced in the intervention group. There was no effect on survival after five years.

Edelman and colleagues (Edelman, Lemon, Bell, & Kidman, 1999) randomly assigned patients with ABC to a cognitive-behavioural intervention in which patients were taught a range of cognitive and behavioural coping strategies and a control group in which standard care was provided. Significant improvements in mood, depression and self-esteem were evident for those completing the intervention but not for those completing the control condition. These improvements were not maintained three and six months post-intervention. Survival after five years revealed no differences between the two groups. Morgenstern and colleagues (Morgenstern, Gellert, Walter, Ostfeld, & Siegel, 1984) delivered an intervention to breast cancer patients that aimed to enhance discussion of cancer-related issues as well as the coping efforts of meditation and positive mental imagery and a group of controls matched on prognostic factors that chose not to participate. Survival analysis five and fifteen years post-intervention revealed no significant effect of intervention on survival.

4.2.4 Meta-Analysis of Intervention Studies

Although it is clear that some interventions have offered significant and important improvements in psychological wellbeing, the effect of coping on survival is unclear. A recent meta-analysis conducted by Smedslund and Ringdal (2004) has gone some way to clarifying this issue. The meta-analysis considered 14 intervention studies of more than 2500 participants. The interventions were diverse but mainly included education, support and skills training. A range of variables was accounted for in the analysis and included age, gender, type of cancer, extensive of disease, cancer treatment received, randomisation, type of control group and format of intervention (group or individual). The results revealed no overall effect of intervention and this did not change when considering randomised versus non-randomised studies. There was, however, a

significant effect of format of treatment with individual interventions significantly prolonging survival but no effect of group interventions (Smedslund & Ringdal, 2004).

4.2.5 Summary

From the research conducted, it cannot be said with certainty that coping influences the development and/or progression of breast cancer. A case may be made for the role of emotional suppression in the development of cancer. Numerous studies, reviews and meta-analyses have found an association between this construct and the development of breast cancer. To date, emotional suppression or similar constructs (such as repression, minimisation, or denial) have been defined differently in each study but it can be broadly claimed that it is characterised by the denial and/or suppression of emotions experienced, avoidance of conflicts, and excessive social desirability and compliance. It is suggested that future research delineates the various elements of emotional suppression that are thought to diminish survival (Giese-Davis & Spiegel, 2002).

Nonetheless, the lack of methodological integrity of the empirical research means that further research is needed to clarify the influence of coping on development and progression. Generally, research has been hampered by small sample sizes, use of samples with varying diagnoses and prognoses, use of measures with questionable reliability and validity, the lack of definitions of coping assessed and their distinction from similar constructs, a failure to account for risk factors and medical variables in a small number of earlier studies and a biased focus on trait coping as this approach was popular at the time of much of the research (Goldstein & Antoni, 1989; Stone et al., 1988; van Elderen, Maes, & Dusseldorp, 1999).

In intervention studies, further issues are the failures to adequately describe interventions, to assess different components of interventions individually, and to assess changes in coping post-intervention as a manipulation check as well as the selection bias of participants self-referring to participation and the inadequacy of control groups (de Ridder & Schreurs, 2001). All of these methodological issues have made it difficult to interpret the findings and need to be overcome in future research. Until these findings are replicated, instructing patients to adopt a manner of coping that is at odds with their usual coping responses may cause undue pressure. If the results are spurious, this may

be considered unnecessary if not unethical (Garssen & Goodkin, 1999; Petticrew et al., 2002)

4.3 Coping and the Diagnosis of Breast Cancer

Attention has shifted from the role of coping in the development and progression of breast cancer to adjustment to diagnosis of the disease. This topic has garnered the focus of much research over the past two decades. The research of better quality consists of moderate to large samples, the use of reliable and valid coping measures, and statistical analyses that account for confounding medical variables. The results of these studies appear to indicate that avoidance and/or emotion-focused coping results in poorer psychological adjustment at diagnosis and up to one year post-diagnosis, regardless of the way in which coping is measured or how adjustment is defined or measured. The remaining studies are hampered by numerous shortcomings. The most common include the use of cross-sectional designs, relatively short-term follow-ups, small sample sizes, samples of cancer patients receiving varying diagnoses, prognoses and treatments, inadequate coping and outcome measures, a failure to account for medical variables, and differences in the conceptualisation of adjustment (Brennan, 2001).

4.3.1 Avoidance Coping

Two cross-sectional studies investigated coping in patients with breast cancer. Friedman and colleagues (Friedman, Baer, Lewy, Lane, & et al., 1988) assessed coping in almost 70 patients diagnosed with EBC and ABC who were between 2 and 225 months post-diagnosis. The results revealed that greater use of avoidance was associated with higher levels of distress and lower levels of adjustment to domestic life. A second study of more than 55 patients with EBC assessed coping between 1 and 26 months post-diagnosis. Similarly, the results showed greater use of avoidance was associated with lower levels of psychological wellbeing.

When considering the patients' adjustment within three weeks of diagnosis, a sample of more than 35 patients with EBC reported use of coping strategies. As previously outlined, the coping strategies included cognitive avoidance, behavioural avoidance, positive focus, distancing and seeking social support. The results showed that those using more cognitive avoidance experienced higher levels of negative mood (Stanton & Snider, 1993). Similar results were reported in another study investigating coping and

adjustment at around six months post-diagnosis. More than 60 women diagnosed with EBC reported on coping, psychological distress, and quality of life at diagnosis and approximately seven months post-diagnosis. Avoidant coping at diagnosis was associated with greater psychological distress and poorer quality of life at follow-up (McCaul et al., 1999).

In an investigation with a longer follow-up, 70 women with EBC reported coping strategies and psychological adjustment at diagnosis to twelve month follow-up. Avoidance predicted greater fear of cancer recurrence while active acceptance at diagnosis predicted less distress (Stanton, Danoff-Burg, & Huggins, 2002). A study with a larger sample of more than 130 patients diagnosed with EBC and ABC investigated coping and distress one week post-surgery, and three, six and twelve months post-surgery. The results revealed that the use of more behavioural disengagement at three months predicted greater distress at six months (Culver, Arena, Antoni, & Carver, 2002).

In a smaller study of less than 60 patients with EBC undergoing surgery, coping strategies and distress was assessed one day pre-surgery, ten days post-surgery, and three, six, and twelve months post-surgery. In terms of concurrent distress, denial and behavioural disengagement were positively related to distress at all time points. Restraint coping pre- and post-surgery was positively related to distress. When trying to predict distress over time, denial and behavioural disengagement at three months predicted distress at six months. Interestingly, distress post-surgery was also found to predict more use of denial, behavioural disengagement, and distraction at three months only (Carver, Pozo, Harris, Noriega, & et al., 1993).

A limited number of studies have investigated the long-term association between coping and adjustment. A study of 70 EBC patients reported on use of cognitive and behavioural approach and avoidance strategies at three months and three years post-diagnosis. Again, the use of more behavioural approach and less cognitive avoidance and negative emotional expression were associated with lower levels of distress at three months. Although these associations were not found at three years, the use of more passive resignation at three months did predict distress at three years (Hack & Degner, 1999, 2004).

A more fine-grained analysis of the association between coping and adjustment in the long-term was performed by Heim and colleagues (Heim, Valach, & Schaffner, 1997). They employed both self- and observer-rated measures of coping and adjustment every three to six months for three to five years. This enabled the investigation of patterns in coping and adjustment across specific treatments well into the period of survivorship. Results indicated significant patterns existed between coping and adjustment to diagnosis during hospitalisation, chemotherapy and rehabilitation but not convalescence or metastasis. When dichotomising patients into those with high and low levels of adjustment, those experiencing good adjustment reported more passive cooperation, acceptance-stoicism, and self-control, and less resignation, rumination, and denial coping. More resignation and rumination, and less self-control coping were related to more distress (Heim et al., 1997).

4.3.2 Emotion-Focused Coping

There is also some evidence for the association between emotion-focused coping and poorer adjustment at diagnosis and up to 6 months post-diagnosis. Epping-Jordan and colleagues (Epping-Jordan et al., 1999) investigated dispositional optimism, coping strategies and psychological adjustment to breast cancer in 80 EBC and ABC patients at diagnosis, three and six month follow-up. At diagnosis and six month follow-up, the use of emotion-focused disengagement coping was associated with higher levels of anxiety and depressive symptoms. Also at six month follow-up, problem-focused disengagement was associated with higher levels.

Comparative results were also evident in a study of coping strategies, perceived control and levels of anxiety and depressive symptoms in 70 women with breast cancer at diagnosis and at three and six month follow-ups. After controlling for initial levels of symptoms, emotion-focused disengagement coping predicted higher levels of symptoms at six months (Osowiecki & Compas, 1999). Lastly, in a study of more than 70 women with breast cancer and their partners, Ben-Zur and colleagues (Ben-Zur et al., 2001) assessed coping strategies, psychological distress, and psychological and social adjustment. Patients', partners' and dyads' use of emotion-focused coping were associated with higher levels of distress and lower levels of adjustment in patients.

In contrast, emotion-focused strategies have been associated with better adjustment post-diagnosis. Over 90 women diagnosed with EBC were assessed 20 weeks post-completion of treatment and after a three month follow-up. Those who reported expressing emotions regarding cancer were found to have significantly fewer medical appointments for cancer-related morbidities, enhanced physical health and vigour, and decreased distress compared to those low in emotional expression. Those reporting greater emotional expression and perceived social support also had improved quality of life (Stanton et al., 2002).

4.3.3. Summary

As indicated, there are many studies that have investigated the role of coping in the adjustment to a breast cancer diagnosis. Much of this research contains methodological shortcomings and as a result, only the better quality studies were considered. Of those, there appears to be associations between avoidance and emotion-focused coping and poor adjustment to the diagnosis of breast cancer. Poor adjustment has been defined as elevated levels of general distress, anxiety and depressive symptoms, and reduced levels of quality of life and to a lesser extent reduced physical functioning.

Despite these consistencies, there are a number of problems with the research that preclude any firm conclusions on the role of coping in adjustment to diagnosis. Typically, coping was only assessed at one time point. As stated, the strategy approach expects coping strategies to fluctuate significantly over time and in response to different stressful situations so one assessment of coping would not be sufficient to link coping with outcomes. The length of follow-ups also varied and did not appear to be tied to significant milestones in the breast cancer journey. Instead, follow-ups often included women undergoing different treatment at different stages of treatment. Lastly, a broad range of coping was assessed with little description of the nature or aim of the forms of coping. It is difficult to ensure that attempts to compare studies assessing similar forms of coping are successful.

4.4 Coping and the Treatment of Breast Cancer

In response to the past literature's tendency to view the process of coping with breast cancer as a unitary stressor, more recent research has viewed it as a more complex situation consisting of several stressors, each of which may require particular coping

efforts (Auerbach, 1989). Research has shifted from examining overall adjustment at any point post-diagnosis to the focus on the experience of discrete treatments in the breast cancer experience. Indeed, as outlined, Heim and colleagues (Heim et al., 1997) intensive study of coping over a five year period emphasised that the strongest relationships between coping and outcomes occur during specific phases of the breast cancer journey. Few studies have been conducted to date so the following outline includes research involving patients with breast and other cancers. The results suggest that coping may play a significant role in the experience of specific treatments, in terms of both physical and psychological wellbeing.

One of the first treatments experienced, breast surgery, often involves significant pain and analgesic use. To determine whether such pain and analgesic use is influenced by coping efforts, Jacobsen and Butler (Jacobsen & Butler, 1996) assessed the use of catastrophising and cognitive coping strategies and self-reported pain and analgesic use in the three days of recovery following surgical intervention in around 60 patients diagnosed with EBC. The results indicated that catastrophising was associated with increased pain and analgesic use while there was no effect of cognitive coping strategies. A more recent study investigated the more broad experience of pain. A sample of almost 70 women diagnosed with EBC or ABC experiencing pain, either from cancer or cancer-related treatment, reported on the severity of the pain and its impact on functioning. Active coping strategies were associated with increased, and passive strategies with reduced, physical functioning whereas catastrophising was associated with greater distress (Bishop & Warr, 2003).

Coping and the experience of chemotherapy has been investigated in several studies, no doubt due to the treatment's ability to significantly impact on physical and psychological wellbeing. A study of 55 patients with EBC reported their use of coping strategies, and the levels of side effects and distress experienced on days one, three and seven after the first chemotherapy infusion. Participants were divided into those with a confrontive, confrontive-avoidant, avoidant-resigned or resigned form of coping. The results found that those with a confrontive form of coping reported lower levels of distress than those using confrontive-avoidant or avoidant-resigned coping and fewer side effects than those using confrontive-avoidant, avoidant-resigned or resigned coping (Shapiro, Boggs, Rodrigue, Urry, & et al., 1997).

The same design was employed in a study conducted by Manne and colleagues (1994). More than 40 patients diagnosed with EBC reported their use of coping strategies, and levels of side effects and positive and negative affect after the first infusion. Results indicated that confrontive and escape-avoidance coping was associated with more negative affect and physical side effects while distancing, self-control and positive reappraisal was associated with more positive affect. The relationship between escape-avoidance coping and negative affect remained significant after accounting for physical side effects but this was not the case for confrontive coping. The relationships between distancing, self-control and positive reappraisal was still significantly associated with more positive affect after accounting for side effects. Physical side effects were significantly and positively associated with negative but not positive affect.

In a final study, Lerman and colleagues (Lerman et al., 1990) investigated the use of monitoring (information seeking) and blunting (information avoidance) coping styles and levels of nausea and distress reported by almost 50 patients with varying cancer diagnoses undergoing adjuvant chemotherapy. Patients were assigned to receive either relaxation training or standard care before chemotherapy. Overall, the results showed that blunting was associated with less anxiety, depression and nausea during and following chemotherapy while monitoring was associated with more anxiety and nausea before and during chemotherapy. The relaxation training group reported significantly less post-treatment nausea compared to control groups and those in the relaxation training group that reported a blunting coping style experienced significantly lower pre-treatment anxiety than those with a monitoring style. This may be because relaxation involves distraction, a strategy that is consistent with the blunting but not monitoring coping style.

In a related vein, Burish and colleagues (Burish, Snyder, & Jenkins, 1991) delivered four interventions aimed at enhancing the experience of 60 cancer patients undergoing chemotherapy for varying diagnoses. Patients were randomly assigned to one of the four single-session preparatory interventions including; relaxation with guided imagery, general coping skills, both relaxation and coping skills, and a routine clinic treatment. Details of the coping skills training were not detailed but consisted generally of education and suggestions as to how to cope with certain side effects. The outcomes

included self-, nurse- and family-observations of side effects and distress as well as physiological measures of arousal after five consecutive infusions. Compared to baseline measures, the coping skills intervention increased knowledge about cancer and its treatment, reduced negative affect and anticipatory nausea and vomiting while the relaxation intervention reduced negative affect and vomiting (Burish et al., 1991).

4.4.1 Summary

Similar methodological problems are evident in this literature as those already reviewed. In addition, though, the outcomes assessed have been determined by researchers and may therefore fail to account for the expectations and goals of participants. This makes it difficult to determine whether coping was effective (Stone et al., 1988). The use of such methodology implies that while certain coping strategies are not considered intrinsically good or bad, the outcomes of these strategies are. However, each study typically included the use of several outcome measures which may increase the likelihood of comprehensively capturing the effects of coping (Auerbach, 1989).

4.5. Mechanisms of Coping and the Experience of Breast Cancer

While much attention is bestowed on the effect of coping on the experience of breast cancer, significantly less has focused on the mechanisms by which coping affects experience. The most common idea is that psychological factors bring about hormone changes, which influence immunological functioning, which in turn increases or decreases the chance for tumours to develop and grow. The way in which coping might do this is two-fold. First, coping might involve engagement in healthy habits that serve to reduce the risk of breast cancer. For example, coping may include behaviours that help maintain a healthy weight, abstaining from alcohol and attending routine mammography (Garssen & Goodkin, 1999; Gerits, 2000; Lazarus & Folkman, 1984).

Second, coping might lead to physiological states that in turn increase or decrease the opportunity for tumours to develop (Garssen & Goodkin, 1999). For example, it has been suggested that states of high physiological arousal may reduce immune-system functioning and therefore, allow tumours to develop. Coping efforts may increase arousal by failing to prevent or ameliorate the stressful situation. This may be due to the intractability of the situation, ineffectiveness of coping efforts, or deficits in coping abilities or resources. Coping efforts may fail to regulate emotional distress in the face

of the stressful situation. Again, this may be due to the ineffectiveness of coping efforts or deficits in abilities and resources. Thirdly, coping may involve exacerbation of the stressful situation. Lastly, coping efforts may aggravate the existing circumstances, result in negative consequences that add to the stressfulness of circumstances or impede more effective coping efforts (Gerits, 2000; Lazarus & Folkman, 1984). Further research is clearly needed to elucidate these potential mechanisms.

4.6 Conclusions

The empirical literature on coping and the aetiology, progression, diagnosis, and treatment of breast cancer has yielded many and varied significant results. Although it has been claimed that differences in the theoretical approaches to coping and problems in methodology and measurement are considered so fundamental that it is impossible to make any definitive statements regarding the efficacy of coping (Stone et al., 1988), several conclusions can be made.

Coping does not appear to play an unequivocal role in the development or progression of breast cancer. However, there is sufficient research to indicate a possible role of emotional expression in enhanced survival that deserves further investigation. When doing so, it is suggested that the aspect of emotional expression that is responsible for enhancing survival is delineated (Gerits, 2000). The use of avoidance and/or emotion-oriented coping has been associated with poorer psychological adjustment to the diagnosis of breast cancer. Although the research is hampered by a range of methodological shortcomings, there does appear to be a consistent link across samples, methods of assessment, and lengths of follow-up.

Of particular interest, however, is the role of coping in specific treatments. Little research currently exists and the results to date have been conflicting. Nonetheless, it is a direction that needs to be pursued. To ensure a comprehensive understanding of the role of coping in specific treatments, it is suggested that future research is prospective in design, includes a sample of women with similar diagnoses, focuses on well-defined and assessable forms of coping, and assesses a range of outcomes.

CHAPTER FIVE

Monitoring and Blunting Coping Styles and the Clinical Experience of Breast Cancer

The theoretical and empirical literature on coping and the breast cancer experience clearly indicates that dispositional coping styles are an important field of investigation. They offer the possibility of considering coping as a dynamic process and at the same time, provide an overall picture of the habitual way in which people cope and how this might affect a range of outcomes (Miller, 1995). In order to investigate these coping styles further, the following chapter will outline the dispositional approach of monitoring and blunting coping styles. This will include an outline of the theory guiding the monitoring and blunting concepts, definitions of monitoring and blunting, and the physical and psychological effects of the use of monitoring and blunting, with supporting empirical research. To date, there has been a significant amount of research conducted on the impact of monitoring and blunting coping styles and the experience of a range of medical issues. Where possible, research investigating the experience of breast cancer will be detailed.

5.1. Definitions of Monitoring and Blunting Coping

Monitoring and blunting represent two orthogonal dimensions of coping. Monitoring refers to the tendency to seek out and attend to information about stressful situations, referred to as threat-related information. Threat-related information may be internal or external. In the case of breast cancer, internal information may concern breast symptoms (for example, a lump) and external information may concern information about breast cancer. Blunting refers to the tendency to turn attention away from and inhibit the processing of information about stressful situations. Typically, people with a preference for monitoring and blunting are referred to as monitors and blunters respectively (Hock, Krohne, & Kaiser, 1996; Miller, Combs, & Kruus, 1993).

5.2 Minimax Hypothesis

Miller proposed the monitoring and blunting coping styles as part of the minimax and monitoring and blunting hypotheses (Miller, 1979b, 1989; Miller et al., 1993). In order to understand the way in which people cope with stressful situations, Miller proposed the minimax hypothesis. The hypothesis states that people are motivated to limit the

amount of stress they have to endure. To do this, people try to minimise how stressful a situation can become.

5.3 Monitoring and Blunting Hypothesis

To understand how people might minimise stressfulness, Miller (1979b; 1989; 1993) proposed the monitoring and blunting hypothesis. This hypothesis states that in order to minimise the stressfulness of a situation, people may employ the two coping styles of monitoring and blunting. The hypothesis also states that the effectiveness of each style depends on the controllability of the situation. In a controllable situation, monitoring is most effective. A controllable situation enables people to perform actions that will mitigate the stressfulness of the situation. Although monitoring may involve an initial increase in emotional arousal as the information about the stressful situation is sought out, arousal will decline as the actions that will mitigate the stressfulness of the situation are performed.

Alternatively, in an uncontrollable situation, blunting is most effective. Monitoring will heighten arousal with no offsetting benefits as no actions exist that allow the stressfulness of the situation to be alleviated whereas blunting will enable an avoidance of the threat-related information and therefore will result in a reduction in arousal. It has also been hypothesised that by reducing arousal levels, the more relaxed way in which the stressful situation is experienced may serve to mitigate the stressfulness of the situation, although there is no empirical evidence to date that confirms this idea (Miller, 1979b, 1989; Miller et al., 1993).

5.4. The Effects of Monitoring and Blunting Coping

A significant amount of empirical research illustrates that monitoring and blunting coping styles affect the way in which stressful situations are experienced. Miller has proposed the Cognitive-Social Health Information Processing (C-SHIP) (Miller & Diefenbach, 1998; Miller, Green, & Bales, 1999c) model and the Monitoring Processing Model (MPM) (Andrykowski et al., 2002; Miller, Rodolletz, Schroeder, Mangan, & Sedlacek, 1996a; Tercyak et al., 2001) in order to outline the broad effects of monitoring and blunting coping. The many areas in which the coping styles are thought to influence include encoding, expectancies and values, psychological and physical wellbeing, self-regulatory strategies and coping strategies. The following section will

outline the theory and supporting research pertaining to the influence of monitoring and blunting coping on these areas. Of note is that the models were developed for research regarding the experience of cancer patients so a significant amount of the research investigating monitoring and blunting concerns cancer patients.

5.4.1 Encoding

Encoding refers to the way in which the stressful situation is perceived and interpreted (Miller et al., 1999c). Monitors' encoding of information about stressful situations appears to differ from blunters' in two ways. Monitors perceive stressful situations to be more threatening and more likely than blunters. The influence of monitoring and blunting on encoding has been illustrated by research conducted in the laboratory and in the medical setting. In the laboratory setting, a sample of undergraduate students were asked to complete measures of monitoring and blunting and trait anxiety before rating the perceived threatfulness of a range of situations varying in stressfulness, controllability and predictability. After controlling for trait anxiety, the results reveal that monitors perceived all situations as more threatening than blunters (Muris & de Jong, 1993). The same results were reported in a second sample of women from the general population (Muris, de Jong, & Suvrijn, 1995a).

In the medical setting, a sample of gynaecological patients from a low socio-economic and minority background were recruited. They had all received an abnormal Pap smear result and were scheduled to undergo a follow-up diagnostic procedure. Patients were asked to report their level of concern about the seriousness of their medical condition and its future course. The results showed that monitors were more concerned about the seriousness of their condition and its future course than blunters (Miller, Roussi, Altman, Helm, & Steinberg, 1994). Similar results were reported in a sample of patients attending a health clinic with acute illness symptoms. The results revealed that monitors reported similar levels of concern about the seriousness of their condition and its future course as blunters, despite having less self- and doctor-rated dysfunction and discomfort than blunters. That is, they attended clinics at an earlier stage of illness but were still significantly distressed (Miller, Brody, & Summerton, 1988).

Not only do monitors perceive stressful situations to be more threatening, they also consider them more likely. Studies of people at an increased risk of cancer have

consistently reported greater perceived risk of developing cancer in monitors compared to blunters. One study asked women at risk of developing ovarian and/or breast cancer to estimate their perceived risk of developing the cancer. The results revealed that monitoring was associated with a significantly higher level of perceived risk (Schwartz, Lerman, Miller, Daly, & et al., 1995). Further, in a study of women undergoing a routine mammogram, monitors reported a higher level of perceived risk than blunters regardless of whether they had a family history of cancer (Zakowski et al., 1997).

One study failed to find a relationship between coping styles and perceived risk. A sample of women attending an ovarian cancer clinic for genetic counseling reported their coping styles, family history, and distress prior to consultation. Participants were divided into those who under, over and accurately estimated their levels of perceived risk. When comparing the groups, only distress was associated with over estimation of perceived risk compared to under or accurate estimation of risk. Future research is needed to consider the full range of estimated risk rather than the comparison of groups (Cull, Fry, Rush, & Steel, 2001).

Indirect evidence that monitors perceive stressful situations as more threatening and more likely may be considered to come from recent research regarding coping styles and the performance of health promoting behaviours. In one study participants were offered the opportunity to undergo a range of genetic tests. It was found that those high in monitoring were more interested in genetic testing than those who were low in monitoring (Shiloh, Ben-Sinai, & Keinan, 1999). In a second study, a sample of students and the community participated in a study in which they were asked to indicate the extent to which they engage in a range of health promotion and disease detection behaviours. The results indicated that participants reporting the use of the monitoring coping style reported more engagement in both health promotion and disease detection behaviours (van Zuuren & Dooper, 1999).

These results are particularly pertinent to women diagnosed with EBC. It has been consistently demonstrated that perceived risk of recurrence is one of the major concerns of women with EBC (Curran et al., 1998; Dow et al., 1996; Tomich & Helgeson, 2002). Risk perceptions are often highest once active treatment has been completed (Lethborg, Kissane, Burns, & Snyder, 2000). At this point, many women feel vulnerable to

recurrence as they are no longer engaged in treatments that are working to reduce their risk. As such, risk perceptions are strongly associated with distress at the beginning of survivorship and after many years (Curran et al., 1998; Dow et al., 1996; Johnson Vickberg, 2001; Kissane et al., 1997; Tomich & Helgeson, 2002; Wenzel et al., 1999). Recent attempts to reduce risk perceptions via education about objective risk of recurrence have been of limited success (Kent, Howie, Fletcher, Newbury-Ecob, & Hosie, 2000; Weinstein et al., 2004). Indeed, it has been argued that risk perceptions are based on psychological factors (Weinstein et al., 2004), perhaps one of which is coping style.

5.4.2 Expectancies and Values

The second area in which the coping styles affect the experience of stressful situations consists of expectancies and values about one's ability to deal with the stressful situation. Miller (1999c) has claimed that monitors are less confident in their own ability to cope with stressful situations and instead are more confident in others' abilities than blunters. In other words, monitors appear to have less internal and more externally oriented locus of control beliefs. Locus of control beliefs refer to the extent to which the outcomes of stressful situations are controlled by a person's actions (internal locus of control) or by external factors such as luck, fate or chance (chance locus of control) and other more competent people (powerful others locus of control). In the case of the health setting, these people might consist of family, friends, or health professionals such as doctors and nurses (Wallston, Wallston, Kaplan, & Maides, 1976; Wallston, 1989; Wallston, Stein, & Smith, 1994).

In a laboratory setting, undergraduate students were asked to report on coping styles, locus of control beliefs and coping strategies commonly used in stressful situations. The results indicated a positive association between monitoring and internal locus of control but no relationship with external locus of control beliefs (van Zuuren & Wolfs, 1991). Further support has been reported in studies performed in the medical setting. In a study described previously, it was reported that patients attending a health clinic for acute illness symptoms reported greater concern about their condition and its future course. The results also showed that despite their concern, monitors preferred to take a passive role in decision-making regarding the treatment options for the illness compared to blunters (Miller, 1988).

Similarly, indirect support for this idea comes from an intervention study of dental patients. Patients undergoing dental treatment were given headphones which instructed them to focus on using either monitoring or blunting coping strategies. Although there was no effect of coping style on experience of anxiety, pain or distress during treatment, the use of monitoring was associated with enhanced self-efficacy (Muris, de Jongh, van Zuuren, Ter Horst, & et al., 1995b).

Conversely, some research has suggested that monitoring is associated with more external locus of control beliefs while blunting is associated with more internal locus of control beliefs. Women who had recently received a diagnosis of EBC reported their preferred level of decisional control. Those patients with a coping style consisting of low cognitive avoidance and high behavioural approach (which may be considered similar to monitoring) reported a significantly more active role in decision-making than patients with a moderate to high cognitive avoidance and low to moderate approach coping style (Hack & Degner, 1999).

Indirect support for the idea that monitors have chance and powerful others locus of control beliefs and blunters have internal locus of control beliefs comes from a study of women from the general population. Women reported their locus of control beliefs, perceived risk, and breast cancer screening behaviour. The results showed that internal locus of control beliefs were associated with low levels of perceived risk. As stated, low perceived risk is characterised by blunting and therefore, it may also be the case that blunting is also associated with internal locus of control beliefs (Rowe, Montgomery, Duberstein, & Bovbjerg, 2005).

Perhaps monitoring is equally associated with both internal and powerful others locus of control. In line with the minimax hypothesis, it may be hypothesised that in controlling situations monitors' information seeking enables them to discern actions that will mitigate the stressful situation, thus enhancing internal locus of control beliefs. Alternatively, in uncontrollable situations monitors' information seeking makes them keenly aware of their limitations in controlling stressful situations, thus enhancing powerful others locus of control beliefs (Miller et al., 1988). Future research is needed to clarify this point.

When considering women diagnosed with EBC, it has been clearly shown that locus of control beliefs have an important role in the engagement in health care decision-making and health promotion and disease prevention behaviours. For example, it has been shown that those with more internal locus of control beliefs prefer an active role in decision-making with medical professionals while those with more chance and powerful others locus of control beliefs prefer medical professionals make decisions regarding patients' health care (Helmes, Bowen, & Bengel, 2002). In addition, it has been shown that an internal locus of control is associated with participation in cancer screening (Aro, de Koning, Absetz, & Schreck, 1999; Borrayo & Guarnaccia, 2000; Bundeck, Marks, & Richardson, 1993; Fajardo, Saint-Germain, Meakem, Rose, & Hillman, 1992; Franco et al., 2000; Glenn & Moore, 1990; Murray & McMillan, 1993; Patterson et al., 2003) and healthy lifestyle behaviours (van Zuuren & Dooper, 1999).

5.4.3. Psychological and Physical Wellbeing

The third area in which monitoring and blunting are thought to affect information processing of stressful situations is psychological and physical wellbeing. It is perhaps unsurprising that monitors, with their tendency to encode stressful situations as more threatening and likely and less controllable, report poor psychological and physical wellbeing in response to stressful situations compared to blunters. Monitors report poorer wellbeing in response to the initiation of a stressful situations and this distress is maintained over time while blunters report less distress and this distress declines gradually throughout the stressful situation (Miller, 1996; Miller et al., 1993; Miller et al., 1999c).

In the laboratory studies previously outlined, students were told they might receive an electric shock and they could listen to an audio channel that provides information about the shock or music. At the start of trials, monitors reported more anxiety and recorded greater physiological arousal than blunters. Across the trials, monitors maintained these levels of anxiety and arousal but blunters lower levels gradually declined over time (Miller, 1979b; Miller, 1987).

In a sample of women diagnosed with breast and/or ovarian cancer and their relatives were tested for the presence of two genetic mutations that increase the risk of these

cancers. Participants were asked to report their monitoring coping style and levels of psychological distress pre- and post-test results. The results showed that those scoring high on monitoring reported greater distress pre-test but not post-test (Tercyak et al., 2001). Similar results were reported in a second study previously outlined. Children who had undergone invasive dental procedure reported their coping styles, use of monitoring and blunting strategies and levels of distress. A preference for monitoring, especially those with a preference for both monitoring and blunting, displayed higher levels of self- and observer-rated anxiety than those with a preference for blunting or neither monitoring nor blunting (Miller, Roussi, Caputo, & Kruus, 1995).

Further studies were conducted in which patients' levels of distress were assessed throughout a more prolonged stressful situation. A study outlined in which patients with acute illness symptoms attended a clinic and rated their levels of distress, discomfort, and symptom improvement prior to and five days post-medical consultation. Monitors showed more distress and discomfort prior to and following the consultation compared to blunters (Miller et al., 1988).

Similarly, the experience of and recovery from an invasive diagnostic procedure was investigated in a sample of gynaecological patients. Subjective, physiological and behavioural measures of distress were measured before, during and following the procedure. Monitors continued to report more pain and discomfort in the week following the procedure than blunters (Miller & Mangan, 1983). Interestingly, half of the participants received voluminous information and the other half received minimal information about the procedure. Greater subjective and physiological arousal was reported by patients who received the information intervention inconsistent with their coping style. That is, monitors and blunters were more distressed when they received minimal and voluminous information respectively (Miller & Mangan, 1983).

Patients with a range of cancer diagnoses reported their levels of anxiety, depression, nausea and vomiting before, during, and following chemotherapy treatment. The results showed that monitoring was associated with more anxiety and nausea before and during chemotherapy whereas blunting was significantly and positively associated with less anxiety, depression and nausea before, during and following chemotherapy (Lerman et al., 1990). A follow-up study examined a sample of women with a family history of

breast cancer undergoing either an individualised breast cancer risk counselling session or a general health education session. Again, the results showed that monitoring was associated with heightened psychological distress up to 3 months post-sessions, regardless of session type (Lerman et al., 1996).

These results are of great importance as they provide some possible explanation of the variation in physical and psychological wellbeing reported by women with EBC undergoing treatment, particularly for those who experience poor wellbeing during and many months following treatment (Beisecker et al., 1997; Bower et al., 2000; Castellon et al., 2005; de Jong et al., 2002b; Falleti et al., 2005; Frost et al., 2000; Jansen et al., 2005; NHMRC & NBCC, 2001; Nordin et al., 2001; Sadler & Jacobsen, 2001; Schagen et al., 1999; Schou et al., 2004).

Even studies in which participants were instructed to employ a monitoring or blunting coping style, despite their dispositional preferences, found that monitoring was associated with greater distress. A sample of undergraduate students was instructed to employ monitoring or blunting coping strategies when exposed to a series of aversive slides. Dispositional coping styles, subjective ratings of psychological distress and objective ratings of physiological arousal were recorded. After controlling for the influence of coping style, monitoring was associated with greater subjective distress but not objective arousal (Muris, De Jong, Merckelbach, & van Zuuren, 1994a).

A second study was conducted in which patients undergoing invasive dental work were instructed to use monitoring and blunting coping. Patients reported on the levels of anxiety, pain and distress they experienced during the treatment. The results contradicted that of the previous study. There was no effect of imposed coping style on anxiety, pain or distress (Muris et al., 1995b). It is possible that there are differences in the extent to which patients were able to adhere to the coping strategies dictated which may have accounted for the contradictory results.

5.4.4 Self-Regulatory Strategies

Miller (1998; 1999c; 1996a) states that the declines in psychological and physical wellbeing reported by monitors are due to the engagement in certain self-regulatory strategies. Self-regulatory strategies refer to efforts aimed at dealing with the stressful

situation and consist of the use of intrusive and avoidant ideation. Monitors' encoding of stressful situations as highly threatening and high likely means that they experience greater levels of distress than blunters. This distress is maintained due to the activation of intrusive ideation. Intrusive ideation consists of persistent, automatic thoughts, feelings and images activated in conscious awareness about a stressful situation.

According to Horowitz and colleagues' (Horowitz, Field, & Classen, 1993; Horowitz, Wilner, & Alvarez, 1979) model of the stress response, intrusive ideation is a necessary experience of adjusting to and assimilating information about the stressful situation. Intrusive ideation enables people to review the information about the stressful situation experienced and incorporate it into existing knowledge about the self and world. Sometimes, the nature of the stressful situation means that information about the situation is at odds with the existing knowledge about the self and world. In this case, intrusive ideation is continually experienced in working memory until the discrepancy is resolved and the information assimilated.

In response to this elevated distress, it is further proposed that a second self-regulatory strategy is triggered. Avoidant ideation refers to attempts to avoid the review of information caused by intrusive ideation in order to reduce distress. Examples of avoidant ideation might include strategies to suppress, distract or deny the intrusive thoughts. While avoidant ideation may be effective in reducing distress in the short-term, they cannot prevent the experience of intrusive ideation in the longer term. This is because as stated, intrusive ideation will be continually experienced until processing of the experience is complete. It is thought that the reduction in distress through avoidance strategies means avoidance efforts are relaxed, which in turn results in the recurrence of the information into working memory (Diefenbach, Miller, & Daly, 1999; Horowitz et al., 1993; Miller, 1996; Miller et al., 1993; Miller & Diefenbach, 1998).

Therefore, the experience of intrusive and avoidant ideation forms a vicious cycle in which arousal is maintained and the stressful situation is not processed. This cycle of intrusive and avoidant ideation will continue until the information is processed sufficiently to warrant a resolution of the new information into the existing schemas. The arousal caused by the cycle will in turn, facilitate the experience of intrusive and

avoidant ideation (Diefenbach et al., 1999; Horowitz et al., 1993; Miller, 1996; Miller et al., 1993; Miller & Diefenbach, 1998).

Empirical evidence shows that monitoring is associated with the use of intrusive and avoidant ideation. In a sample of gynecological patients undergoing an invasive diagnostic procedure previously described, monitors reported higher levels of intrusive thoughts and avoidance compared to low monitors (Miller et al., 1994). Similarly, the relationships between monitoring, intrusive and avoidant ideation, and distress were examined in women at increased risk of ovarian cancer. All patients had at least one first-degree relative that had been diagnosed with the disease. The results showed that monitoring predicted increased levels of intrusive ideation, which in turn, predicted increased distress (Schwartz et al., 1995).

Miller and colleagues (Miller et al., 1996a) conducted similar research in women with human papillomammary virus (HPV), a virus which increases the risk of cervical cancer, and men who were HIV positive. The results indicated that monitoring was associated with intrusive ideation, both of which in turn predicted distress. The relationships between monitoring, intrusive and avoidant ideation and distress were stronger in the sample of men than women. This is expected given that the effects of monitoring and blunting are thought to be more evident in highly stressful situations and HIV is considered a more serious condition than HPV. Further, although they did not investigate the role of monitoring and blunting, two studies have confirmed the relationships between intrusive and avoidant ideation and distress in samples of women undergoing infertility treatment compared to healthy controls (Miller et al., 1998) and women with and without a history of breast cancer undergoing a routine mammography (Zakowski et al., 1997).

As suggested, adjustment to a stressful situation coincides with a reduction in the levels of intrusive and avoidance ideation and distress. Women at high risk of developing breast and/or ovarian cancer underwent genetic counseling and received either an enhanced genetic counseling information session or a general health information session. The results demonstrated that those who underwent the enhanced session reported a decline in levels of intrusive, avoidance and distress one-week post-intervention compared to those who underwent the general session. Thus, it is suggested

that the provision of enhanced information facilitated the understanding and assimilation of information about genetic risk and therefore, a reduction in intrusive and avoidant ideation and distress (Miller et al., 2005). Clearly, the cross-sectional nature of the assessment of intrusive, avoidance and distress mean that it is impossible to determine whether the relationships are causal in these studies.

The results appear to be of particular relevance to women diagnosed with EBC, many of whom have reported declines in physical and psychological health over an extended period of time. It is possible that it is not only coping styles but the consequent use of the self-regulation strategies of intrusive and avoidant ideation that serve to maintain the levels of poor wellbeing (Beisecker et al., 1997; Bower et al., 2000; Castellon et al., 2005; de Jong et al., 2002b; Falletti et al., 2005; Frost et al., 2000; Jansen et al., 2005; NHMRC & NBCC, 2001; Nordin et al., 2001; Sadler & Jacobsen, 2001; Schagen et al., 1999; Schou et al., 2004).

5.4.5. Coping Strategies

As indicated, monitoring and blunting coping styles are fairly stable dispositional attributes that are thought to influence the actual coping strategies utilized in stressful situations. This has been demonstrated in a series of studies confirming that monitoring and blunting coping styles are associated with corresponding coping strategies. For example, monitoring has been shown to be associated with the corresponding coping strategies of control-predictability coping, seeking social support and active coping (Ben-Zur, 2002; Shiloh et al., 1999). Blunting has been associated with the corresponding coping strategies of avoidance, wishful thinking and escape (Ben-Zur, 2002; Shiloh et al., 1999; van Zuuren & Wolfs, 1991). Then again, monitoring has also been linked to the coping strategies of wishful thinking and escape, strategies indicative of blunting coping (van Zuuren & Wolfs, 1991). Some of this research has then demonstrated that coping styles affect psychological distress via the coping strategies (Ben-Zur, 2002; Shiloh et al., 1999).

5.4.6 Conclusions

There is a significant amount of research investigating the experience of stressful situations in regards to monitoring and blunting coping styles. The results of the studies have indicated that monitoring and blunting are associated with different ways of

responding to stressful situations. Monitoring is associated with the perception that stressful situations are more threatening and likely, more external locus of control regarding stressful situations, elevated levels of psychological and physiological distress, intrusive and avoidant ideation, and perhaps certain coping strategies, compared to blunTERS.

While these findings are significant in terms of understanding the variation in experience of stressful situations, there are some consistent methodological problems with the research. Small samples are common which may have affected the results reported (Miller & Mangan, 1983; van Zuuren, 1993, 1994), although the difficulties of recruiting a clinical sample are widely acknowledged. Despite claims that monitoring and blunting are orthogonal coping styles, much research has simply investigated those that report a preference for monitoring (Miller et al., 1996a; Schwartz et al., 1995; Tercyak et al., 2001). Therefore, little is known about the outcomes of preferring both or neither monitoring and blunting.

This trend is due in part to the initial methods of measuring monitoring and blunting. Early research investigated monitoring and blunting as a single dimension with high monitoring/low blunting at one end (known as monitors) and low monitoring/high blunting at the other (blunTERS) (Miller, 1987). In an attempt to overcome this, it has been suggested that people are categorised into one of four coping styles: high monitoring/low blunting, high monitoring/high blunting, low monitoring/high blunting, and low monitoring/low blunting (Krohne, 1989; McKinnon, 2001; Miller, 1996; Miller et al., 1993). Given the small samples, this method was not widely employed.

Alternatively, cluster analysis has been used to investigate the coping styles that exist in a sample and typically, the analysis has demonstrated similar results to the four styles described (Hack & Degner, 1999; Shapiro et al., 1997; Voss, Kolling, & Heidenreich, 2006). More recent research has considered the two styles as separate dimensions, and reported on the outcomes of a preference or lack of preference for monitoring and/or blunting (Krohne, 1993; Miller et al., 1995).

5.5 Adaptiveness of Monitoring and Blunting Coping

5.5.1 Advantages of Monitoring

Reasons for preferring a monitoring coping style are manifold. As stated in the monitoring and blunting hypothesis, monitoring in controllable stressful situations may enable people to determine and perform actions that will minimise the stressfulness of the situation. Empirical evidence exists that monitors' information seeking may have helped them to engage in adaptive actions that reduced the stressfulness of situations (Miller et al., 1993; Roth & Cohen, 1986). In one study, women at increased risk of ovarian cancer were offered a medical procedure that lowers risk. After the provision of information, high monitors appeared to use the information to make an adaptive decision about the procedure compared to low monitors. Significantly more high monitors chose not to have the procedure, an adaptive decision given that none of the women were medically appropriate candidates for the procedure (Fang, Miller, Daly, & Hurley, 2002). Also, monitoring has been associated with the tendency to perform health promotion behaviour such as getting regular medical check-ups, participating in regular exercise, and following a healthy diet (van Zuuren & Dooper, 1999).

Alternatively, monitoring may enable people to identify actions that others can perform to reduce the stressfulness of the situation. Indeed, it has been proposed that information seeking may allow monitors to instigate and maintain contact with these more competent people (Miller, 1996; Miller et al., 1993). This may explain the contradictory associations between monitoring and internal and external locus of control beliefs. That is, monitoring may provide information regarding what actions need to be performed by whom to effectively deal with the stressful situation. However, there is evidence that contradicts this idea. People who prefer to monitor have been found to do so even in situations that do not allow instrumental actions to be undertaken (Miller, 1979a).

Several additional benefits of monitoring have been proposed, but limited research exists to support the idea. It is possible that people engage in monitoring to gain information regarding the severity, probability, nature, and duration of the stressful situation. This reduces uncertainty and identifies safety signals, both of which serve to reduce arousal (Krohne, 1993; Miller et al., 1993; Shiloh et al., 1999). Another benefit is that monitoring may allow people to develop a sense of personal meaning about their experience in stressful situations. It has been shown that people who have a sense of

meaning about their experiences report lower levels of distress or greater adjustment than those who are not able to (Thompson, 1981). This proposition relates to the idea outlined that monitoring allows the activation of intrusive ideation which in turn, facilitates the emotional processing of stressful situations, which has received some support in the empirical literature (Manne, Glassman, & Du Hamel, 2001; Miller et al., 2005; Schwartz et al., 1995).

5.5.2 Disadvantages of Monitoring

Despite the number of potential benefits of monitoring, there are several disadvantages to consider. Research involving a range of settings and samples has shown that monitoring tends to lead to increased distress (Miller, 1979b; Miller et al., 1996a; Miller et al., 1995; Muris & de Jong, 1993; Schwartz et al., 1995; Tercyak et al., 2001; van Zuuren, 1993). The association between monitoring and elevated distress has led Miller to speculate on two disadvantages of this coping style, although little or no evidence exists to support these ideas as yet. First, it has been suggested that this heightened level of distress may inhibit monitors from engaging in appropriate coping responses. Miller provides an example of this in the medical setting. She explains that a high level of distress may encourage monitors to seek help for illness too readily. This may then have unintended negative consequences whereby monitors may be considered an annoyance by health professionals resulting in them being ignored when their need is real and urgent (Miller, 1996).

Second, it has also been hypothesised that monitoring may put people at risk of developing anxiety disorders (Miller, 1992). At least one study of children has suggested that a monitoring style is associated with more symptoms of anxiety disorders (Muris et al., 2000). If a monitoring coping style does increase the risk of anxiety disorders, it might be expected that it affects the outcomes of therapy. To date, evidence of both short- and long-term therapeutic outcomes in people with a spider phobia has been mixed, with studies showing no influence of coping styles (Muris et al., 1993), a favourable effect of monitoring (Steketee, Bransfield, Miller, & Foa, 1989) and an unfavourable effect of monitoring (Muris, de Jong, Merckelbach, & Van Zuuren, 1993a; Muris, Merckelbach, & de Jong, 1995c).

5.5.3 Advantages of Blunting

On the other hand, a preference for blunting tends to result in lower levels of distress in response to stressful situations. In turn, this may enable blunters to gradually approach the situation, rather than becoming highly aroused and overwhelmed by it. This may then facilitate other positive experiences such as enabling a sense of hope and mastery throughout the situation. At present no research has been conducted to confirm these ideas (Roth & Cohen, 1986).

5.5.4 Disadvantages of Blunting

There are also some possible disadvantages of blunting. A preference for blunting may put people at risk of failing to identify stressful situations. In cases where the threat is identified, blunting may also interfere with the collection of information regarding the execution of coping responses necessary to reduce the stressfulness of the situation. An example Miller provides from the medical setting is the presentation of illness at such a late stage that the appropriate treatment is not received. Although past research has shown that blunters attending a health clinic for acute illness symptoms present at a later stage than monitors, it is not known whether this later stage is appropriate to the illness experienced, or whether it was too late for effective treatment. Further research is needed to clarify this point. There is also concern that blunting may result in emotional numbness and disruption to the processing of and adjustment to the stressful situation (Roth & Cohen, 1986). The limited research investigating longer term stressful medical situations does indicate that blunters adjust better than monitors (Lerman et al., 1996; Miller, 1988; Miller & Mangan, 1983).

5.6 Effectiveness of Monitoring and Blunting Coping

Overall, it is hypothesised that monitoring and blunting coping are most effective when individuals are able to flexibly apply them in accordance with the characteristics of stressful situations. This would maximise the benefits and minimise the costs of employing each coping style. According to the monitoring and blunting hypothesis, this refers to the deployment monitoring strategies when the situation is controllable and blunting strategies when the situation is uncontrollable. Further, it has been suggested that the use of both styles within controllable and uncontrollable situations would be the most adaptive. For example, people could use monitoring for long enough to implement problem-solving strategies but also distract themselves with blunting periodically in

order to modulate levels of distress (Krohne, 1993; Miller et al., 1999c; Roth & Cohen, 1986; Voss et al., 2006). Evidence that people can be taught to use monitoring and blunting coping makes it likely that future coping interventions will be designed and implemented to enhance outcomes of stressful situations (Muris et al., 1994a; Muris et al., 1995b).

However, the extent to which coping styles can be flexibly employed may be constrained by dispositional preferences for monitoring and blunting as well as personal and situational characteristics. In the first instance, it has been shown that although coping styles employed varied slightly according to beliefs about the extent to which electric shocks were avoidable, a number of participants still employed their dispositional coping style (Miller, 1979b). Situational factors may include the controllability, probability and predictability of stressful situations. For example, Miller suggests that stressful situations that are highly controllable and probable, highly threatening, imminent and of long duration are difficult to blunt as they are so confronting when compared to situations that are improbable, relatively unthreatening, remote and of short duration (Miller, 1979b, 1990). Person-specific characteristics may include the ability to accurately perceive these characteristics in stressful situations (Krohne, 1993). Further research is needed to gain an understanding of these factors and the extent to which they constrain the flexible use of monitoring and blunting.

5.7 Mechanisms of Monitoring and Blunting Coping

There is some speculation as to why people display a particular coping style. Miller has not provided an explicative basis for the coping styles, leaving other theorists to propose potential mechanisms of monitoring and blunting but little empirical research has been conducted to investigate these propositions. The most coherent approach is outlined by Krohne (1989), who states that people experience arousal in response to stressful situations for two reasons: the presence of ambiguity and aversive stimuli. Ambiguity triggers arousal because it signals uncertainty as to what the situation involves and how best to cope with it. Aversive stimuli trigger emotional arousal because they signal the unpleasant effects of the stressful situation (Hock et al., 1996; Krohne, 1989; Krohne, 1993).

The experience of uncertainty can prompt concerns about the nature, severity, predictability, controllability, and duration of the stressful situation, a response that may be called a 'fear of danger'. Alternatively, the experience of arousal might lead to concerns about further unbearable increases in arousal, a response called a 'fear of fear'. Krohne believes that people differ dispositionally in the extent to which they are tolerant of uncertainty and emotional arousal. Although these are separate dimensions of tolerance, intolerances of uncertainty and emotional arousal are difficult to regulate simultaneously. That is, monitoring may reduce uncertainty but also increase in emotional arousal while blunting may reduce emotional arousal but also increase uncertainty. People with a low tolerance of uncertainty will be motivated to employ a monitoring coping style while people with a low tolerance of emotional arousal will be motivated to employ a blunting style. Given that people are thought to dispositionally vary in their intolerance of uncertainty and arousal, they are also presumed to dispositionally vary in monitoring and blunting coping styles (Hock et al., 1996; Krohne, 1989; Krohne, 1993; Wilson, 1984).

People with neither a monitoring nor blunting style are tolerant of both uncertainty and emotional arousal. They are thought to be able to flexibly apply monitoring or blunting according to the situation demands and therefore, are considered to be the most effective copers (Hock et al., 1996; Krohne, 1989; Krohne, 1993). Alternatively, people who display both a monitoring and blunting style are intolerant of both uncertainty and emotional arousal. They experience negative consequences when employing either monitoring or blunting which leads to the erratic deployment of the coping styles and for short durations. Adhering to one style becomes intolerable, so they are motivated to switch styles before discovering if the coping style is effective for the given situation.

Aside from Krohne's (1989; 1993) theory, numerous and diverse propositions have been made that attribute the effects of monitoring and blunting to differences in perception and cognition. First, it has been said that monitoring is associated with greater sensitivity in the perception of physiological arousal. That is, they can detect changes in somatic arousal more quickly. This suggestion was prompted by evidence suggesting that monitors seek medical advice earlier in illness than blunters (Miller, 1988).

Two studies have investigated this assertion. Women completing stressful arithmetic, drawing and cold-presser tasks were asked to indicate the level and change in somatic arousal. The results indicated that monitors were no more accurate in their estimations than people who did not prefer to monitor, although questions regarding the accuracy of the measures of somatic arousal were raised (Steptoe & Voegelé, 1992). In a similar study of participants completing stressful tasks, the results showed there was no relationship between monitoring and blunting and the accuracy of somatic arousal perception (Steptoe & Noll, 1997).

It has also been suggested that monitoring is associated with an increased attentional bias towards threat. That is, monitors attend more to threat-relevant information in the environment. Attentional bias was examined in a sample of female undergraduate students completing a series of Stroop tasks: a colour-naming, neutral word, and dental treatment-word tasks. After accounting for trait and dental anxiety, there was no effect of coping style on performance (Muris, Merckelbach, & de Jongh, 1995d).

The effects of monitoring, some suggest, are due to a greater capacity for imagining or elaborating on threat-relevant information. A sample of women was presented with a list of written stressful situations. They were instructed to indicate the extent to which they were able to imagine and elaborate on the situations described. There existed no association between monitoring and blunting and the capacity to imagine or elaborate on stressful situations (Muris et al., 1995a). Further research is needed to determine whether this finding is replicated when experiencing stressful situations rather than just reading about them.

In a similar vein, it has also been proposed that monitoring is associated with a reduced capacity for controlling thoughts. Interestingly, in a study of people with dental phobia, results indicated that monitoring was associated with less ability to control thoughts (Muris, De Jongh, van Zuuren, & ter Horst, 1994b). An extension of this study compared people with dental phobia and controls. Results indicated that monitoring was positively associated with the frequency and believability of negative thoughts about dental treatment and negatively with the ability to control these thoughts. On the other hand, blunting was negatively associated with frequency and believability of thoughts

but positively with cognitive control (Muris, De Jongh, Van Zuuren, & Schoenmakers, 1996).

Others have suggested that monitoring is not a unique construct but rather taps into existing constructs that are associated with increased somatic perception, such as trait anxiety, hypochondriasis, or medical fears (Muris & Van Zuuren, 1992; Muris et al., 1994c; Muris, van Zuuren, & de Vries, 1994d; Steptoe & Voegelé, 1992). Research has shown that people with high levels of trait anxiety attend more to body symptoms. To date, evidence exists that monitoring and trait anxiety are unrelated (Muris et al., 1994c; Steptoe & Voegelé, 1992) although significant but small associations have been reported on occasion (Kohlmann, 1993; van Zuuren et al., 1999). This idea also contradicts evidence suggesting that monitors and blunterners experience equivalent levels of arousal in situations of low threat (Miller, 1979b). If high monitoring merely reflected high trait anxiety, differences in anxiety levels would be evident in both high and low threat situations.

Similarly, it has been shown that people with hypochondriasis amplify existing body symptoms (Steptoe & Voegelé, 1992). There is only one study to date which has investigated the relationship between perception of somatic arousal, hypochondriasis and monitoring and blunting coping styles. In a small sample of people instructed to assess their somatic arousal during periods of relaxation and stressful cognitive tasks, results indicated there was no relationship between the three constructs (Steptoe & Noll, 1997). Further research is needed to investigate this idea using a clinical sample.

Given that much of the research on monitoring and blunting has been carried out regarding stressful medical situations, it has been argued that monitors' heightened arousal levels can simply be explained by monitors' fear of medical situations. There is evidence that supports this assertion. In studies of undergraduate students, monitoring has been associated with more fears of medical events (Muris et al., 1994d) and blood injury (Muris & Van Zuuren, 1992). However, it may be that monitors are conditioned to fear medical situations as their coping style means they typically experience these situations with great distress and it is this conditioned response that accounts for the association (Muris et al., 1994d).

In all of the research conducted to assess whether the effects of monitoring and blunting can be accounted for by related constructs, there are significant methodological issues. The most common are the use of small, undergraduate samples, the use of either written hypothetical or laboratory-based situations, and the relationships between monitoring and the related constructs are investigated cross-sectionally. Further research is needed to overcome these shortcomings and hence, clarify the relationship between the constructs.

5.8 Measures of Monitoring and Blunting Coping

Several measures of monitoring and blunting have been developed that are similar in format and content. The first measure developed was the Miller Behavioral Style Scale (MBSS: Miller, 1987). It consists of descriptions of four stressful situations that are thought to vary in controllability and predictability. Each situation is followed by three monitoring and three blunting responses. Participants are asked to indicate the extent to which they believe they would employ each option on a five-point Likert scale. The scale yields two subscale scores of monitoring and blunting with higher scores indicating more use of the coping style. Mean split procedures are used to determine those with high/low monitoring and high/low blunting coping styles or scores are utilised as continuous variables.

Originally, the MBSS utilised a dichotomous true/false response format and subscale scores were collapsed across styles to provide an overall continuum with monitoring and blunting at either ends. The response format was criticised as offering little scope for variations in responses. The revised Likert scale version of the MBSS has demonstrated superior internal consistency to the dichotomous version (Muris et al., 1994e; van Zuuren & Wolfs, 1991).

Several versions of the MBSS have been developed. The MBSS has been translated into Spanish with some success (Miro, 1997). At times, researchers have utilised only a selection of stressful situations in a measure in order to create a short-form version (Miro, 1997). This contradicts the purpose of providing a range of stressful situations that differ on important dimension (van Zuuren, 1994; van Zuuren et al., 1996) and perhaps unsurprisingly has received limited empirical support (Miro, 1997). A version for children, known as the Monitoring and Blunting Scale for Children (MBSC), has

also been developed and its limited use to date indicates adequate psychometric properties (Miller et al., 1995; Muris, Merckelbach, Gadet, & Meesters, 2000).

The Threatening Medical Situations Inventory (TMSI: van Zuuren et al., 1996) was developed for use in populations facing stressful health situations. The MBSS was developed in response to feedback from respondents who reported frustration at the scale's focus on what they considered to be irrelevant situations given the seriousness of their issues (Steptoe, 1989). Similar to the MBSS, the TMSI involves the description of four hypothetical stressful situations that differ in degree of threat, controllability and predictability. There are both Dutch and English versions of the TMSI. Much less utilised are the Mainz Coping Inventory (MCI) (Krohne, 1989), the Monitoring-Blunting Questionnaire (MBQ: Muris et al., 1994c), and the Frankfurt Monitoring Blunting Scale (Voss et al., 2006), all of which were developed as alternatives to the MBSS in measuring monitoring and blunting coping styles across general stressful situations, although little is known about their psychometric properties as they have not been widely utilised in empirical research.

Most scales demonstrate adequate internal reliability of .60-.87 (Miro, 1997; van Zuuren et al., 1996) and test-retest reliability of .71-.83 with a two to five week period (Miro, 1997; Rees & Bath, 2000; van Zuuren et al., 1996). Poor internal reliabilities for the blunting subscales have been reported (Bijttebier et al., 2001; Muris et al., 1994c; Rees & Bath, 2000). Several people have suggested that blunting consists of more and varied coping responses than monitoring and that this complexity may not be adequately represented in the scales (Bijttebier et al., 2001; Muris & Schouten, 1994; van Zuuren, 1994). Exploratory factor analysis has revealed two-factor solutions equivalent to the monitoring and blunting scales for some of the scales (Muris & Schouten, 1994; Ong et al., 1999; van Zuuren et al., 1996), although sample sizes have been mostly small. Confirmatory factor analysis has yet to be conducted.

As illustrated, empirical research has shown fairly consistent relationships between monitoring and blunting coping styles and chosen monitoring and blunting options in response to a stressful situation. For example, monitors have been shown to listen to an audio channel presenting information on the possible imminent electric shocks, seek feedback on performance on a cognitive task, and ask more questions during invasive

dental procedures whereas blunters are more likely to listen to an audio channel of music and to avoid feedback on their performance on cognitive tasks, and remain quiet during dental procedures (Miller, 1987; Miller et al., 1995; Muris et al., 1994e).

Construct validity has been demonstrated in several ways. Convergent validity has been demonstrated between the monitoring and blunting scores on the scales outlined above, although not consistently across scales (Bijttebier et al., 2001). Consistent associations have been reported between monitoring and blunting and information seeking behaviours. Participants in laboratory studies with a preference for monitoring consistently seek out information about the task and performance compared to blunters (Miller, 1987). Patients undergoing a series of medical and dental procedures report that they desire more information on the procedure when they are monitors compared to blunters (Miller et al., 1995; Steptoe & O'Sullivan, 1986; van Zuuren et al., 1999). This desire remained even when monitors demonstrated a higher level of existing knowledge (Steptoe & O'Sullivan, 1986). Correspondingly, reported satisfaction with the level of information corresponded with coping style such that monitors and blunters reported greater satisfaction and adjustment when receiving voluminous and minimal information respectively (Agre et al., 2003; Miller & Mangan, 1983; van der Zee, Gallandat Huet, Cazemier, & Evers, 2002; van Zuuren, 1998).

In addition, monitoring and blunting have been associated with relevant coping strategies. For example, monitoring has been significantly and positively associated with information seeking, question-proneness and seeking social support while blunting has been associated with avoidance strategies and negatively with information-seeking (Ben-Zur, 2002; Brown & Bedi, 2001; Miller et al., 1995; van Zuuren et al., 1996), although little or no association between the styles and these strategies has also been reported (Ben-Zur, 2002; Miller et al., 1996a; van Zuuren & Wolfs, 1991). Importantly, no research has investigated the stability of the construct. This is necessary in future research given the strong emphasis on coping styles as a dispositional characteristic.

Discriminant validity has been illustrated by the lack of association between monitoring and blunting themselves (Muris et al., 1994c; van Zuuren et al., 1996), as well as the related concepts of trait anxiety (Muris et al., 1994c; Steptoe & Voegelé, 1992), hypochondriasis (Steptoe & Voegelé, 1992), and repression (Myers & Derakshan,

2000). As mentioned, some correspondence between coping styles and trait anxiety has been reported (Kohlmann, 1993; van Zuuren et al., 1999).

5.9 Conclusions

Monitoring and blunting coping styles are clearly important concepts for investigation. Research concerning the coping styles demonstrates that they are able to account, in part, for the variation in short- and medium-term experience of a range of largely uncontrollable stressful medical situations. The theory and past research suggest that it is in these situations that those with a tendency to monitor are more likely to experience poorer health outcomes, more anxiety and depressive symptoms, more intrusive and avoidant ideation, possess more external locus of control beliefs, and a heightened risk perception compared to those with a tendency not to monitor or a tendency to blunt.

Although the research has gone some way to explaining variations in the experience of stressful situations, further research is needed to clarify a number of issues. Given that the research has been conducted on small, mainly undergraduate samples, research is needed to replicate the results in larger clinical samples undergoing stressful situations. Investigation of the interaction between the monitoring and blunting and its effect on outcomes is necessary. Although theory and empirical evidence has confirmed that monitoring and blunting are mutually exclusive dimensions of coping, there has been few attempts to determine the way in which these coping styles may interact and influence outcomes. It would be valuable to investigate the psychometric properties of the coping style measures employed to ensure they possess adequate reliability and validity.

Research is needed to investigate the influence of monitoring and blunting on both physical and psychological wellbeing. It is also necessary to clarify the theorised relationships between monitoring and blunting coping and related constructs of locus of control beliefs and risk perception. Despite continual reference to such relationships in Milbr's (1996; 1993) theory, little empirical evidence has been conducted to date. The research needs to be extended to include stressful situations and follow-up periods of longer duration to determine whether the experience of a protracted situation is comparable to those of a shorter duration. Research including longer periods of follow-up is needed to determine whether the experience over time remains similar.

5.10 Aims

The present study provides an original and vital extension of the past literature to understand the role of monitoring and blunting coping styles in the physical and psychological experience of adjuvant chemotherapy in women with EBC. A thorough understanding of the experience of adjuvant chemotherapy is long overdue.

Chemotherapy is one of the most difficult challenges facing women diagnosed with EBC. It consists of an intense, rigid and prolonged treatment schedule and its significant short- and long-term physical and psychological wellbeing. Patients' experience of this treatment varies greatly, with some women experiencing severe and serious physical and psychological side effects. Despite this, research has yet to address this issue and identify the reasons why some women experience more side effects and to a lesser extent, distress, than others.

Investigation of coping in experience of breast cancer can be described as extensive in number yet narrow in scope. Research has focused solely on the use of coping strategies at diagnosis and its effect on outcomes several months following diagnosis. The advance of a new area of coping research on monitoring and blunting coping styles provides some hope of better understanding the experience of specific stressful medical experiences. Monitoring and blunting have been investigated in a range of clinical samples undergoing stressful medical procedures and treatments and have been shown to influence the physical and psychological wellbeing experienced in response to such procedures and treatments. It is likely that monitoring and blunting will be able to explain the physical and psychological wellbeing of women with EBC undergoing chemotherapy.

The study will involve determining whether monitoring and blunting coping styles are associated with;

- 1). The levels of anxiety and depressive symptoms experienced before, during and six months following chemotherapy;
- 2). The presence and severity of side effects experienced before, during and six months following chemotherapy;
- 3). The levels of intrusive and avoidant ideation experienced;

- 4). The levels of internal, chance and powerful others locus of control beliefs before, during and six months following chemotherapy; and
- 5). Risk perceptions of future recurrence of cancer six months following chemotherapy in women diagnosed with EBC.

This will be investigated while accounting for differences in women's disease, physical health, and treatment while undergoing adjuvant chemotherapy for EBC.

5.11 Research Questions

The intensive and prospective nature of the study allows the investigation of several research questions:

- 1). The levels of monitoring and blunting experienced; It is predicted that participants will report a wide range of use of monitoring and blunting coping styles.
- 2). The relationship between monitoring and blunting: It is predicted that monitoring and blunting scores will be unrelated to each other, indicating that they are mutually exclusive dimensions of coping.
- 3). The stability of monitoring and blunting over time: It is expected that use of monitoring and blunting coping will be constant over time, indicating that they are stable, dispositional factors.
- 4). The relationship between scores on two widely used measures of monitoring and blunting; It is predicted that monitoring scores and blunting scores on two measures will be highly and positively related, indicating that they are measuring the same coping constructs.
- 5). The levels of anxiety and depression experienced; It is predicted that participants will report a wide range of anxiety and depression throughout and following chemotherapy treatment, reflecting the variation in experience of chemotherapy reported by women undergoing chemotherapy for EBC. It is predicted that levels of anxiety and depression reported will increase prior to and on commencement of chemotherapy treatment and will decrease on completion of chemotherapy treatment and at follow up, indicating the challenging nature of the treatment and as reflected in

the past research. The experience of higher levels of depression than anxiety is expected. Depression is reported more often than anxiety by women post-diagnosis.

6). The levels of side effects experienced; It is predicted that levels of side effects reported will increase prior to and on commencement of chemotherapy treatment and will decrease on completion of chemotherapy treatment and at follow up. Participants are expected to report a wide range of side effects throughout chemotherapy treatment. Again, this is line with the variation in experience reported by women undergoing chemotherapy. It is predicted that levels of side effects will be affected in part by treatment factors, including the chemotherapeutic drugs administered, the anti-emetic medication and GCSF support provided, dose reductions in chemotherapeutic drugs (if any) and treatment delays (if any). It is also expected that side effects will be affected in part by participants' ability to metabolise the chemotherapy drugs. This ability is reflected in the levels of bone marrow, hepatic, and renal functioning. Lastly, it is expected that the side effects reported at follow-up will be affected in part by the administration of radiation and/or endocrine therapy post-chemotherapy completion.

7). The association between monitoring and blunting and the levels of anxiety and depression reported; It is predicted that participants who report the greater use of monitoring or the greater use of both monitoring and blunting will report higher levels of anxiety and depression throughout chemotherapy treatment and at follow-up compared to those who report greater use of blunting. As predicted by Miller's monitoring and blunting hypothesis, it has been consistently found that those who use monitoring or both monitoring and blunting coping styles experience greater levels of psychological distress during and following a stressful situation compared to those using a blunting coping style or neither a monitoring nor blunting coping style.

8). The association between monitoring and blunting and the level of side effects reported; It is predicted that participants who report the greater use of monitoring or the greater use of both monitoring and blunting will report higher levels of side effects throughout chemotherapy treatment compared to those who report greater use of blunting. Again, this reflects Miller's theory and the finding that those who use a monitoring or both monitoring and blunting coping style experience greater levels of

physical distress during and following a stressful situation compared to those using a blunting coping style or neither a monitoring nor blunting coping style.

9). The association between monitoring and blunting and intrusive and avoidant ideation; It is predicted that greater use of monitoring or the greater use of both monitoring and blunting will be associated with higher levels of intrusive and avoidant ideation compared to those who report greater use of blunting, as predicted by Miller's theory and demonstrated by past research.

10). Whether intrusive and avoidant ideation mediate the relationship between monitoring and blunting and anxiety, depression, and side effects; It is predicted that intrusive and avoidance ideation will mediate the relationship between monitoring and blunting and the experience of anxiety, depression and side effects. That is, monitoring and blunting will be indirectly (via intrusive and avoidant ideation) associated with levels of anxiety, depression and side effects experienced throughout and following chemotherapy treatment. Horowitz's (1993) and Miller's (1996; 1993) theories state that intrusive and avoidant ideation are elicited in stressful situations in order to facilitate adjustment to the situation. Miller's theory further adds and research supports (Miller, 1996; 1993) the idea that intrusive and avoidant ideation mediate the relationship between monitoring and blunting and psychological and physical wellbeing.

11). The association between monitoring and blunting and locus of control beliefs; It is predicted that greater monitoring will be associated with more internal and powerful others locus of control but less chance locus of control beliefs. It is predicted that blunting is associated with more chance and powerful others locus of control and less internal locus of control beliefs. This pattern of beliefs has long been proposed by Miller but has been largely unexamined in research. As previously outlined, locus of control beliefs have been implicated in desired role in health care decision-making and engagement in health promotion and disease prevention behaviours.

12). The association between monitoring and blunting and levels of risk perception; It is predicted that monitoring is associated with increased levels of risk perception while blunting is associated with decreased levels of risk perception, as proposed by Miller's

theory and illustrated in limited past research. Risk perceptions have been implicated in poor psychological wellbeing during survivorship.

5.12 Theoretical and Clinical Implications

The intensive and prospective nature of the investigation is one of the first of its kind in the area of chemotherapy for EBC and will provide a number of crucial theoretical and practical implications. In terms of the theoretical benefits, the study will reveal fundamental information about the monitoring and blunting coping styles. Monitoring and blunting will be examined in a moderately large clinical sample undergoing a long-term, uncontrollable and highly stressful situation with a long-term follow-up. The hypothesised relationships between monitoring, blunting and their interaction, and physical and psychological wellbeing, intrusive and avoidant ideation, locus of control orientation, and perceived risk will be explored. This will in turn serve to enhance our understanding of monitoring and blunting coping styles and the nature of the theory of monitoring and blunting coping styles. It will also provide much needed information regarding the reliability and validity of widely used monitoring and blunting measures and the nature of the coping styles.

In terms of the clinical implications, the study will delineate some of the factors that influence women's experience of chemotherapy. The consequence of which are superior medical and psychosocial care. Medical professionals will be able to identify those women at risk of poorer physical and psychological wellbeing due to their chosen coping styles. Once identified, medical professionals will be able to provide additional support to those women at risk of poorer physical wellbeing. For example, they may provide greater supportive medication (such as anti-emetic medication, GCSF support) to those using coping styles that are implicated in increased side effects. An understanding of locus of control beliefs can provide medical professionals with important information about patients' desired role in decision-making and engagement in health promotion and disease prevention behaviours, both of which are critical to survival.

Psychologists will be able develop psychosocial interventions aimed at enhancing effective coping and therefore improving women's physical and psychological wellbeing. The interventions may aim to either reduce the use of coping styles

implicated in poorer outcomes or enhancing those implicated in superior outcomes.

Examining the way in which women effectively deal with their chemotherapy treatment in terms of both physical and psychological wellbeing will constitute a major advance in our understanding and improvement of cancer services.

CHAPTER SIX

Method

6.1 Participants

Participants included women undergoing adjuvant chemotherapy treatment for EBC. The inclusion criteria specified that participants had histologically confirmed EBC, had proficient English language skills (to ensure they could provide informed consent and were able to accurately understand and complete questionnaires), were over the age of 18 years, had no prior history of adjuvant chemotherapy treatment, had no current psychiatric disorder(s) that could impede the accurate completion of questionnaires and were receiving adjuvant chemotherapy treatment in the ACT.

Participants were recruited from four hospitals in the ACT region catering to public and private patients. Most women attended The Canberra Hospital (34.0%), Calvary Hospital (28.3%) and The National Capital Hospital (28.3%). The remaining few participants attended John James Memorial Hospital (9.4%). The Canberra Hospital accommodates public patients, Calvary Hospital accommodates both public and private patients, and National Capital Private Hospital and John James Memorial Hospital accommodate only private patients. Participants were approached by their oncologist, chemotherapy nursing staff or breast care nurse regarding participation in the study. Of the 65 patients referred, 12 (5.4%) were unable to participate; 5 did not have time available to complete the first questionnaire prior to commencing treatment, 4 could not be contacted prior to commencing treatment, 2 reported being too distressed to handle the requirements of participation and 1 declined to undergo treatment.

All participants underwent a selection of diagnostic tests to establish the presence of EBC, as recommended by the NHMRC Guidelines for Clinicians (NHMRC & NBCC, 2001). These tests may have included mammography with or without ultrasound, fine needle aspiration, core biopsy, full blood count and serum biochemistry, chest X-ray, bone scan, liver ultrasound, and chest computed tomography. All participants received a selection of adjuvant treatments to remove the tumour(s) from the breast and any remaining cancer cells in the body, as suggested by the NHMRC Guidelines (NHMRC & NBCC, 2001). Participants underwent surgical intervention, adjuvant chemotherapy, and radiation therapy and/or endocrine therapy. One (1.9%) participant refused to

complete chemotherapy and no reason for non-compliance was provided. One participant (1.9%) died during the course of participation.

Of the 53 participants initially recruited, all completed the initial interview, 46 (86.8%) completed the questionnaire following the first infusion, 47 (88.7%) following the middle infusion, 44 (83.0%) following the final infusion, and 35 (66.0%) at 6-month follow-up. The reasons for failing to complete the questionnaire included poor health and lack of time due to work and family commitments. The initial interview was conducted a mean of 36.19 (16.13) days post-diagnosis, with a range of 14-99 days, and was a mean of 30.17 (12.80) days since final surgery, with a range of 9-64 days. The initial interview was conducted close to the time of first chemotherapy infusion, with a mean of 6.17 (7.62) days and a range of 0-33 days.

6.2 Design

The study was a prospective design. The dependent variables were levels of anxiety, depression, intrusive and avoidant ideation, side effects experienced, locus of control orientations and perceived risk of a breast cancer recurrence. The independent variables were demographic characteristics, health and disease variables, treatment variables and bone marrow, renal and hepatic functioning variables. Demographic variables included age, marital status, level of education, employment status, employment intensity, and occupation. Health variables included referral source, patient health care status, use of anxiolytic medication, use of antidepressant medication, and menopausal status.

Disease variables included method of detection, number of tumours, tumour size, tumour grade, number of affected lymph nodes and oestrogen receptor, progesterone receptor and HER2 statuses. Treatment variables included number of surgeries, type of surgery, performance of axillary dissection, type of chemotherapy regimen, chemotherapeutic drugs, anti-emetic medication and GCSF support received, dose reduction, treatment delay, and hospitalisation. Bone marrow, renal and hepatic functioning variables included neutrophils, bilirubin, alanine aminotransferase, alkaline phosphatase, gamma glutamyl transferase, albumin, urea and creatinine.

6.3 Materials

6.3.1 Demographic Characteristics

Demographic characteristics were collected in the first questionnaire completed prior to commencement of adjuvant chemotherapy treatment. These included marital status, state of residence, level of education, employment status, employment intensity and occupation. Marital status and state of residence were defined and coded according to the National Health Data Dictionary (National Health Data Committee, 2003). Occupation was coded according to the Australian Standard Classifications of Occupations (Australian Bureau of Statistics, 1997).

Marital status consisted of five categories; single/never married, married or de facto, separated or divorced, and widowed. State of residence consisted of two categories; the ACT or NSW (NSW). Level of education indicated the highest level of education attained. Education consisted of five categories; primary school, year 10, secondary school, undergraduate degree, and postgraduate degree. Employment status described whether the participant was currently employed with three categories; employed, unemployed, and retired. Employment intensity described the amount of hours spent in employment and consisted of two categories; full-time or part-time. Occupation consisted of nine categories; managers and administrators, professionals, associate professionals, tradespersons and related workers, advanced clerical and service workers, intermediate clerical, sales and service workers, intermediate production and transport workers, elementary clerical, sales and service workers, and labourers and related workers.

6.3.2 Health and Disease Characteristics

Health characteristics were collected from participants' medical files with the exception of referral source which was noted at the time of referral. Referral source described the source that referred the participants to the project and consisted of three categories; treating medical oncologist, breast care nurse, and chemotherapy clinic nurse. Patient health care status reflected the source of health care funding utilised by the participants and consisted of two categories; public or private health care. The use of anxiolytic and antidepressant medication described whether the participant was regularly taking this medication on throughout chemotherapy treatment and consisted of two categories; yes and no. Menopausal status described the participants' menopausal status on

commencement of chemotherapy treatment and consisted of two categories; pre-menopausal and post-menopausal.

Disease characteristics were collected from participants' medical files. The exception was the method of detection, which was collected in the first questionnaire. Disease characteristics include method of detection, date at diagnosis, tumour type, tumour size, number of affected axillary lymph nodes, histologic grade, oestrogen receptor (ER), progesterone receptor (PR), and HER2 statuses. Method of detection described the way in which participants came to discover the disease for the first time and consists of four categories; self-examination (accidental), breast self-examination, clinical examination by a health professional and routine mammography.

Date of diagnosis was taken to be the date of first surgery. The reason for this is that although a number of diagnostic tests are conducted, the final diagnostic information is obtained at the first surgery. Also, patients may differ slightly in the diagnostic tests completed whereas all received surgery so using the date of first surgery ensures consistency. Tumour type describes the form of breast cancer diagnosed and was recorded according to the Australian Institute of Health and Welfare Breast Cancer in Australia report (AIHW & NBCC, 2006).

Tumour size described the size of the tumour's diameter or in the case of several tumours, the largest tumour's diameter in millimetres. Number of affected axillary lymph node was recorded in numbers starting from zero. Histological grade described the extent to which the tumour is differentiated and consisted of three categories; 1, 2 and 3. One signifies a low grade in which tumours are well differentiated while three is a high grade in which tumours are poorly differentiated. ER, PR and HER2 statuses described the nature of oestrogen, progesterone and HER2 receptor expression and was recorded using two categories; positive or negative.

6.3.3 Treatment Characteristics - Surgery

Information on the surgical intervention(s) received was recorded from participants' medical files. The surgical information collected included the number of surgeries, type(s) of surgery performed, whether axillary dissection was performed, and the date of the first and final surgeries performed. The number of surgeries reflected the number of

surgical interventions performed (excluding axillary dissection). While many patients will undergo one form of surgical intervention, some will undergo more than one. The most common example is when patients undergo breast conserving surgery (BCS) but due to the extent of the disease uncovered during BCS, the patient goes on to receive a unilateral total mastectomy (TM). The type of surgery performed describes form of surgical intervention performed. The types of surgery consisted of four categories; BCS, BCS plus TM, TM, or bilateral TM. The performance of axillary dissection refers to whether the participants underwent surgery to remove the nearby lymph nodes and consisted of two categories; yes or no.

6.3.4 Adjuvant Chemotherapy

Chemotherapy treatment variables were collected from the participants' medical files. The chemotherapy information collected included the chemotherapy regimen prescribed and the chemotherapeutic drugs, anti-emetic medication and GCSF support administered, dose reductions, treatment delays and hospitalisations for the first, middle and final chemotherapy cycles.

Five standard chemotherapy regimens were prescribed and consisted of:

- 1). FEC (5-fluorouracil 600mg/m², epirubicin 100mg/m², and cyclophosphamide 600mg/m² given intravenously on day 1) every three weeks for six cycles;
- 2). Oral CMF (cyclophosphamide 100mg/m², orally on days 1-14, methotrexate 40mg/m² and 5-fluorouracil 600mg/m² both given intravenously) on days 1 and 8 every four weeks for six cycles;
- 3). AC (adrimyacin 60mg/m², and cyclophosphamide 600mg/m² both given intravenously on day 1) every two weeks for four cycles;
- 4). AC/Taxol (adrimyacin 60mg/m², and cyclophosphamide 600mg/m² both given intravenously on day 1 for four cycles, and Taxol 175mg/m² given intravenously on day 1 for four cycles) every four weeks for eight cycles; and
- 5). EC/Taxol (epirubicin 60mg/m², and cyclophosphamide 600mg/m² both given intravenously on day 1 for four cycles, and Taxol 175mg/m² given intravenously on day 1 for four cycles) every four weeks for eight cycles (Chap, Barsky, Bassett, & Haskell, 2001a).

Correspondingly, the chemotherapeutic drugs administered at an infusion were recorded and consisted of five categories; FEC, Oral CMF, AC, EC and Taxol.

The anti-emetic drugs describe the level of anti-emetic medication provided to participants after each treatment in either intravenous or oral form or both. The anti-emetic medication consisted of 4 levels:

- 1). Level 0 - None;
- 2). Level 1 - Single anti-emetic (for example, a 5-HT₃ antagonist, corticosteroid, dopamine receptor agonists, or aprepitant);
- 3). Level 2 - Combination of a 5-HT₃ antagonist and a corticosteroid; and
- 4). Level 3 - Combination of a 5-HT₃ antagonist and a corticosteroid plus an aprepitant and/or anxiolytic.

Typically, levels 0 and 1 are prescribed for patients receiving IV CMF, Oral CMF, and Taxol and levels 3 and 4 are prescribed for AC, EC, and FEC (Grunberg, 2001).

Treatment delay describes the need to postpone the scheduled chemotherapy treatment and consisted of two categories; yes or no. The length of delay (if any) was recorded in days. Dose reduction describes the need to decrease the quantities of drugs administered and consists of two categories; yes or no. The amount of dose reduction (if any) was recorded as a percentage by which the quantity of drugs was decreased. Hospitalisation describes the need for patients to be admitted to hospital for medical treatment following chemotherapy treatment and consisted of two categories; yes or no. The length of hospitalisation (if any) was recorded in days. Delays in treatment, dose reductions and hospitalisations are all indicators of excessive toxicity experienced from the previous chemotherapy treatments.

6.3.5 Bone Marrow, Hepatic and Renal Functioning

To assess the level of bone marrow, hepatic and renal functioning, the date and results of pathology tests of bone marrow, hepatic (liver), and renal (kidney) functioning conducted prior to the first, middle and final chemotherapy cycles were recorded from the ACT Pathology database. Bone marrow, hepatic, and renal functioning are all indicators of the extent to which the body metabolises the chemotherapy drugs.

Increases in the functioning of these indicators means that the body is working hard to deal with the effects of the drugs on the body. Participants whose bone marrow, hepatic and renal functioning is compromised may in turn experience greater side effects.

Bone marrow functioning was indicated by a measure of neutrophils. Neutrophils are one of several types of white blood cell. Neutrophils are made in the bone marrow and move out of the bloodstream into the body's tissue to fight infections. When the body is fighting off infection, neutrophil count increases and very low levels of neutrophils places the body at risk of infections. Renal functioning was assessed by the levels of urea and creatinine. Urea and creatinine are waste substances that are normally cleared from the blood by the kidneys into the urine. When the kidneys' functioning is compromised, the levels of urea and creatinine increase (IDG Books Worldwide, 2000).

Hepatic functioning by measures of bilirubin, albumin, alanine aminotransferase (ALT), alkaline phosphatase (AlkP) and gamma glutamyl transferase (GGT). Bilirubin is a compound that is produced by the breakdown from red blood cells. Bilirubin is used by the liver to make bile for processing substances. Albumin is a protein in the blood that helps regulate the osmotic pressure of blood. Albumin transports substances to the liver for processing. ALT, AlkP and GGT are different types of enzyme that is normally present in the liver and are released into the bloodstream when the liver is damaged. Increased levels of any of these indices indicate the liver may be seriously compromised (IDG Books Worldwide, 2000).

6.3.6 Radiation Therapy

Information recorded on radiation therapy was obtained from participants' medical files. The variables recorded included the receipt of radiation therapy was completed, dates of first and final treatment, length of treatment, and length of time between final treatment and six-month follow-up questionnaire. The receipt of radiation therapy was completed consisted of two categories; yes or no. The length of treatment and the length of time between the final treatment and six-month follow-up were recorded in days.

6.3.7 Endocrine Therapy

Information was also recorded regarding endocrine therapy and included the receipt of endocrine therapy and the type of endocrine therapy prescribed. The receipt of endocrine therapy consisted of two categories; yes or no. The type of endocrine therapy prescribed included three categories; Tamoxifen (a non-steroidal anti-estrogen), Arimidex (an aromatase-inhibitor), and Zoladex (a pituitary downregulator), all prescribed in standard doses for five years.

6.3.8 *Monitoring and Blunting Coping Styles*

The Threatening Medical Situations Inventory (TMSI) (van Zuuren et al., 1996) was used to assess monitoring and blunting coping styles (Appendix A). Participants completed the TMSI as part of the first and final questionnaires, completed prior to and six months following chemotherapy respectively. The TMSI presents participants with four stressful medical situations that differ in the extent to which they are stressful, controllable, and predictable. Participants are asked to indicate the extent to which they would engage in three monitoring and three blunting responses described at the end of each scenario. Responses to the 24-item scale are made on a five-point Likert scale, ranging from one (not at all) to five (very much so).

The TMSI yields two subscale scores of monitoring and blunting, with higher scores indicating a greater use of coping style. Internal consistency is adequate with estimates of 0.66-0.85 for monitoring and 0.78-0.88 for blunting (Brown & Bedi, 2001; Pieterse et al., 2005; van der Zee et al., 2002; van Zuuren et al., 1999). Test-retest reliability is adequate with an estimate of 0.71 for a two week period (van Zuuren et al., 1996). Exploratory factor analysis has confirmed the two-factor structure originally proposed (Ong et al., 1999).

Convergent and discriminant validity is indicated by the pattern of associations between monitoring and blunting scores on the TMSI and corresponding scores of other measures of monitoring and blunting, including the MBSS (Miller, 1987) and MCI (Krohne, 1989). TMSI monitoring scores have been shown to be positively and moderately associated with the MBSS and MCI monitoring scores and the TMSI blunting scores was positively and moderately associated with MBSS and MCI blunting scores (Bijttebier et al., 2001; van Zuuren & Muris, 1993). Predictive validity evident in the association between TMSI-B and observed blunting behaviour such as increased time taken to switch from distracting music to information (Muris et al., 1994d).

The TMSI was considered to be the most appropriate and valid measure of monitoring and blunting in the present sample. Past research indicates that participants with serious health problems find it frustrating to complete measures of general stressful situations which they consider to be irrelevant to their current circumstances. Therefore, it was

expected that the TMSI's inclusion of only stressful medical situations would have increased face validity for the present sample (Steptoe, 1989; van Zuuren et al., 1996). It also avoids the need to create a new scale that addresses the cancer experience specifically as this would be costly and time consuming (van Zuuren et al., 1996). By closely reflecting their current circumstances, it was expected that participants' responses would more accurately reflect what they actually did in their situation, thus improving predictive validity.

The TMSI has been used successfully in a wide range of populations experiencing health concerns, including cardiac patients (Brown & Bedi, 2001; van der Zee et al., 2002), dental surgery patients (van Zuuren et al., 1999), those at high risk of cancer (Lerman et al., 1990; Pieterse et al., 2005; Tercyak et al., 2001), and breast cancer patients (McKinnon, 2001) cancer patients with varying diagnoses and prognoses (Ong et al., 1999).

The Miller Behavioral Style Scale (MBSS) (Miller, 1987) was also used to assess monitoring and blunting scores (Appendix B). The MBSS was completed as part of the final six-month follow-up questionnaire. As previously outlined, the MBSS was included as a comparison of monitoring and blunting use in general stressful situations as opposed to the stressful medical situation included in the TMSI. Given that the past research has suggested the MBSS lacks face validity in medical patients and the need to keep the questionnaires brief during treatment, a decision was made to include the MBSS only at the follow-up.

Like the TMSI, the MBSS presents participants with four stressful but general situations that differ in the extent to which they are stressful, controllable, and predictable. Participants are asked to indicate the extent to which they would engage in the four monitoring and four blunting responses described at the end of each scenario. Responses to the 32-item scale are made on a five-point Likert scale, ranging from one (not at all) to five (very much so).

The MBSS yields two subscale scores of monitoring and blunting, with higher scores indicating a greater use of coping style. The estimates of internal consistency range from .65-.79 for monitoring and .41-.76 for blunting (Miller, Shoda, & Hurley, 1996b;

Muris et al., 1995a; Muris & Schouten, 1994; Muris et al., 1994c; Rees & Bath, 2000; Schwartz et al., 1995; van Zuuren & Wolfs, 1991). Concern exists at the number of low internal reliability estimates reported for the blunting subscale. A test-retest reliability estimate was .71 for five weeks for the monitoring subscale (Rees & Bath, 2000). The two-factor structure has been confirmed using exploratory factor analysis in several studies (Muris & Schouten, 1994).

As previously outlined in the discussion of the TMSI, convergent and divergent validity have been demonstrated in the expected pattern of relationships between monitoring and blunting scores on a range of measures, including the TMSI and MBSS (Bijttebier et al., 2001; Muris et al., 1994c; van Zuuren et al., 1996). Predictive validity has been demonstrated in studies in which monitoring is associated with monitoring behaviours in real-life stressful situations. For example, high monitors looked at a light signalling performance level during a test more often than low monitors (Miller, 1987; Muris et al., 1994e). The MBSS has been used in a range of cancer samples including women at risk of breast or ovarian cancer (Andrykowski et al., 2002; Cull et al., 2001; Miller et al., 1999a; Miller et al., 1994; Rees & Bath, 2000), breast cancer patients (Gard, Edwards, Harris, & McCormack, 1988) and cancer patients with varying diagnoses and prognoses (Petersson et al., 2002).

6.3.9 Intrusive and Avoidant Ideation

The Impact of Events Scale (IES) (Horowitz et al., 1993) was used to measure intrusive and avoidant ideation (Appendix C). The IES was completed as part of all questionnaires provided, before, during and six months following chemotherapy treatment. The IES is a 15-item scale which yields two subscale scores of intrusive ideation and avoidant ideation. Participants are asked to indicate the extent to which they are experiencing intrusive and avoidant ideation described on a four-point Likert scale. Higher scores indicate greater levels of intrusive and avoidant ideation. The measure is brief, is easy and efficient to administer, has good face validity, and is the most widely accepted and utilised measure of intrusive thoughts and avoidance (Thewes, Meiser, & Hickie, 2001).

The IES was originally used in populations of war veterans who were at risk of post-traumatic stress disorder. However, the realisation that populations experiencing

stressful situations also experience intrusive and avoidant ideation coupled with the items' lack of reference to a specific situation has meant the IES's use has been extended to populations experiencing a range of stressful situations. The measure has been used widely in breast cancer patients (Bleiker, Pouwer, van der Ploeg, Leer, & Ader, 2000; Cordova et al., 1995; Hampton & Frombach, 2000; Johnson Vickberg, 2001; Nordin et al., 2001), although it should be noted that IES scores can vary according to severity of cancer, age at diagnosis, and treatment received (McBride, Clipp, Peterson, Lipkus, & Demark-Wahnefried, 2000).

Exploratory factor analysis has confirmed the two-factor structure which discriminates intrusive and avoidance items (Thewes et al., 2001). Internal consistency is adequate with estimates ranging from .86-.89 for intrusive ideation and .77-.90 for avoidant ideation and test-retest over a 14-day period of .75-.80 (Andrykowski et al., 2002; Baider, Ever-Hadani, & De-Nour, 1999; Devine, Parker, Fouladi, & Cohen, 2003; Thewes et al., 2001). Concurrent validity has been demonstrated by moderate positive associations between the subscales (Epping-Jordan, Compas, & Howell, 1994) as well as with similar constructs such as psychological distress (Baider & De-Nour, 1997; Thewes et al., 2001; Vickberg, Bovbjerg, DuHamel, Currie, & Redd, 2000), anxiety and depression (Bleiker et al., 2000; Nordin et al., 2001), health status and complaints (Bleiker et al., 2000; McBride et al., 2000), problems with health care (Hampton & Frombach, 2000), family history of breast cancer (Andrykowski et al., 2002; Baider et al., 1999), and over-performance of breast self-examination (Erblich, Bovbjerg, & Valdimarsdottir, 2000). Discriminant validity has been demonstrated with negative and moderate associations with engagement in health behaviours (McBride et al., 2000).

6.3.10 Locus of Control Beliefs

The Multidimensional Health Locus of Control Scale Form C (MHLOC-C) (Wallston et al., 1976; Wallston et al., 1994) was used to assess the extent to which a person believes their current illness is determined by their own behaviour (internal locus of control), chance, fate, or luck (chance locus of control) and other powerful people such as health professionals or friends and family (powerful others locus of control) (Appendix D). The MHLOC scale was completed as part of all questionnaires provided, before, during and six months following chemotherapy treatment. There are several forms of the MHLOC scale. The original forms, Forms A (MHLOC-A) and B (MHLOC-B), were

designed to address locus of control beliefs about general health (Wallston et al., 1976). These scales were increasingly utilised in samples of patients with chronic illness which led to the development of the illness-specific MHLOC-C scale. Given that health locus of control beliefs are thought to differ according to experience, it is thought that a measure specific to an illness would be more appropriate and valid. The MHLOC-C was used to measure locus of control beliefs in the present study (Wallston et al., 1994).

The MHLOC-C scale is an 18-item scale that yields three subscale scores of internal, chance, and powerful other locus of control. Participants are asked to indicate the extent to which they agree with statements regarding locus of control orientation and to consider the items according to their cancer disease. Higher scores indicate a greater level of orientation (Wallston, 1989). The measure is brief, easy and efficient to administer, and is the most widely accepted and utilised measure of health locus of control beliefs in breast cancer patients (Bourjolly, 1999; Bremer, Moore, Bourbon, Hess, & Bremer, 1997; Grassi & Rosti, 1996; Watson, Pruyn, Greer, & van den Borne, 1990).

The MHLOC-C subscales have adequate internal reliabilities with estimates ranging from .63-.80 (Chen, Deng, & Chang, 2001; Dahnke, Garlick, & Kazoleas, 1994; Holm, Frank, & Curtin, 1999). Exploratory and confirmatory factor analysis indicates a three-factor solution distinguishing the three forms of locus of control orientation is most commonly obtained (Dahnke et al., 1994; Malcarne, Fernandez, & Flores, 2005). The MHLOC-C has demonstrated excellent discriminant and convergent validity. As expected, medical patients with chronic disease report less internal and more chance and powerful others locus of control beliefs compared to those with less severe and short term disease (Dahnke et al., 1994). Evidence for discriminative validity has been demonstrated in the lack of association between the subscales of the MHLOC-C (Dahnke et al., 1994; Wallston, 2005b).

Convergent validity is illustrated in the positive and moderate to strong associations between subscale scores and the corresponding subscales of locus of control scales, including the MHLOC-A and MHLOC-B (Wallston, 2005a). Further convergent validity is evident in the positive associations with constructs to which the subscales are expected to be related. Internal LOC is associated with the performance of health-

promoting behaviours (Schultheis, Peterson, & Selby, 1987) and lower perceived risk of disease (Rowe et al., 2005). Chance LOC is associated with the God Locus of Control scale (Wallston et al., 1999), and powerful others LOC is associated with medical professional-dependent cancer screening procedures such as pap smears and clinical breast examinations (Bundek et al., 1993). Patients with illnesses that are less amenable to personal control, such as cancer and aplastic anaemia, report more chance LOC beliefs whereas those with illness that are in part controllable, such as diabetes, report more internal LOC beliefs (Dahnke et al., 1994; Wallston, 2005b).

6.3.11 Risk Perception

To date, risk perceptions of the recurrence of breast cancer, indeed any type of cancer, has been identified as an important construct in qualitative (Vickberg et al., 2000) but rarely quantitative research (Mullens, McCaul, Erickson, & Sandgren, 2004). As a result, there exists no widely accepted and utilised measure of risk perceptions of recurrence. A similar construct, risk perceptions of developing breast cancer for the first time, has received considerable attention in more recent research investigating the effects of genetic counselling (Culver, Burke, Yasui, Durfy, & Press, 2001; Hurley, Miller, Costalas, Gillespie, & Daly, 2001). The present study therefore modified a commonly used method of measuring the risk perceptions of developing breast cancer in order to investigate perceived risk of recurrence, the Risk Perception Scale (RPS: Appendix E). The RPS was completed as part of the final six months follow-up questionnaire.

Measures of perceived risk of developing breast cancer have instructed participants to estimate their personal risk using numbers (Bottorff et al., 2004; Cunningham et al., 1998; Gil et al., 2003; Weinstein et al., 2004), verbal descriptors (Absetz, Aro, & Sutton, 2002; Andrykowski et al., 2002; Bowen et al., 2003; Culver et al., 2001; Diefenbach et al., 1999; Facione, 2002; Kent et al., 2000), or both (Absetz, Aro, Rehnberg, & Sutton, 2000; Lipkus, Green, & Marcus, 2003; Lipkus, Klein, Skinner, & Rimer, 2005; Rowe et al., 2005). Numerical estimates often involve either providing a percentage estimate (Bottorff et al., 2004; Gil et al., 2003; Lipkus et al., 2003; Lipkus et al., 2005; Rowe et al., 2005), or choosing one of a selection of numerical estimates (Cunningham et al., 1998; Weinstein et al., 2004). Verbal estimates involve providing an estimate response to a single (Absetz et al., 2000; Andrykowski et al., 2002; Bowen

et al., 2003; Diefenbach et al., 1999; Kent et al., 2000; Lipkus et al., 2005) or several (Absetz et al., 2002) questions according to verbal descriptors on a Likert scale.

Research indicates a lack of correspondence between numerical and verbal estimates (Absetz et al., 2000; Lipkus et al., 2003; Lipkus et al., 2005; Rowe et al., 2005). It is thought that the discrepancy is due to a lack of understanding of the meaning of numerical risk estimates (Absetz et al., 2000). Also, perceived risk may be based on different factors compared to actual risk. Research has shown little or no correspondence between objective and subjective risk of cancer (Kent et al., 2000; Weinstein et al., 2004). Furthermore, providing information on personal objective risk estimates does not appear to change personal perceived risk (Weinstein et al., 2004). This may explain why some research reports significant overestimations of risk but little psychological distress (Absetz et al., 2000).

To qualify the estimates of personal risk, some researchers have obtained a measure of comparative risk. That is, the extent to which personal risk is thought to be greater or lesser than that of peer risk. Comparative risk is thought to give an indication of how vulnerable people feel to developing cancer. Comparative risk estimates have been calculated in four ways: by subtracting numerical or verbal estimates of peer risks from personal risk (Bottorff et al., 2004; Cunningham et al., 1998) and by asking participants directly to indicate whether their risk is greater or lesser than peers' risk in numerical or verbal terms (Culver et al., 2001; Facione, 2002; Lipkus et al., 2005; Rowe et al., 2005; Weinstein et al., 2004).

The construct validity of perceived risk of developing cancer has been demonstrated repeatedly with scores correlating with other constructs in theoretically expected ways. For example, greater levels of perceived risk is associated with increased distress, worry, and thoughts about breast cancer (Cunningham et al., 1998; Kent et al., 2000), increased acceptance of genetic counselling (Culver et al., 2001), increased adherence screening behaviour (Bowen et al., 2003; Gil et al., 2003) but less benefit from screening adherence (Gil et al., 2003).

The present study asked participants to consider "What do you think is the likelihood you will develop breast cancer in the future?" as a measure of personal risk perception

and “What do you think is the likelihood that a woman the same age and who has had the same diagnosis and treatment will develop breast cancer in the future?” as a measure of peer risk perception. Responses were indicated on a seven-point Likert scale ranging from one (none) to seven (very likely). A measure of comparative risk perception was calculated by subtracting the score of peer risk from personal risk.

6.3.12 Anxiety and Depressive Symptoms

The Hospital Anxiety and Depression Scale (HADS: (Zigmond & Snaith, 1983) was used to measure the number and severity of anxiety and depressive symptoms (Appendix F). The HADS was completed as part of all questionnaires provided, before, during and six months following chemotherapy treatment. The HADS yields two subscale scores of anxiety and depressive symptoms. Higher scores indicate higher levels of anxiety and depression symptoms. The subscales have demonstrated adequate internal consistency, with estimates ranging from .68-.93 for anxiety and .67-.90 for depression (Bjelland, Dahl, Haug, & Neckelmann, 2002).

Both exploratory and confirmatory factor analyses have consistently reported a two-factor solution that distinguishes anxiety and depression items (Bjelland et al., 2002; Osborne, Elsworth, Sprangers, Oort, & Hopper, 2004). Alternative solutions of one (Johnston, Pollard, & Hennessey, 2000) and three (Rodgers et al., 2005) factors have also been reported but these analyses have been hampered by small sample sizes and diverse samples of patients (Bjelland et al., 2002; Rodgers et al., 2005).

Concurrent validity has been demonstrated with comparisons to other widely used and accepted measures of anxiety and depressive symptoms, such as the Spielberger State-Trait Anxiety Inventory (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983), Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), Symptom Check List 90 Scale (Derogatis & et al., 1974). Correlations with these scales ranged between .49 and .83 (for a review, see (Bjelland et al., 2002). Scores on the HADS have also been shown to correlate with other constructs in theoretically expected ways. For example, scores are significantly and positively correlated with side effect burden and negatively correlated with quality of life (Dausch et al., 2004).

Discriminant validity is evident in research showing that factor analysis of items from measures of both psychological and somatic symptoms showed all items of the HADS loaded onto the psychological factor, demonstrating that the HADS measures psychological, rather than somatic, symptoms of anxiety and depression (Johnston et al., 2000). It is the ability of the HADS to measure anxiety and depression without contamination of somatic symptoms, also manifest in health conditions, that has led to its use in samples of medical patients, including those with breast cancer (Groenvold et al., 1999; Montazeri et al., 2000; Osborne et al., 2004; Osborne et al., 2003; Turner et al., 2005). Although some concerns about its narrow focus on the depression symptoms of anhedonia exists (Hall et al., 1999; Love et al., 2002).

6.3.13 Chemotherapy Side Effects Scale

There is no widely used and accepted self-report measure of adjuvant chemotherapy side effects with demonstrated reliability and validity. The chemotherapy regimens prescribed to patients with breast cancer have changed continually over the years. These changes have been in response to research demonstrating the improved effectiveness of certain regimens over others. The continual change has made it difficult to develop a reliable and valid measure for use over an extended period of time. As a result, much research has utilised general measures of negative physical symptoms although concern exists regarding the specificity and sensitivity of the measures in breast cancer patients.

For the purposes of the present study, a self-report measure was created to assess the most commonly experienced side effects in patients undergoing adjuvant chemotherapy for EBC. A list of side effects was generated in response to the literature and in consultation with the Director of Clinical Cancer Services in the ACT. The aim was to develop a scale that was brief but covered the most common side effects. The Chemotherapy Side Effects Scale was a 12-item scale that yielded one overall score of side effects (CSES) (Appendix G). The side effects included lack of appetite, fatigue, sore muscles, pain, constipation, nausea, vomiting, difficulty sleeping, and memory problems.

The response scale was based on the Common Toxicity Criteria for Adverse Events (National Cancer Institute, 1999, 2003). The Criteria are widely used and accepted manual for rating the level of impairment caused by physical symptoms. Responses

were made on a five-point Likert scale that lists the levels of impairment according the Criteria. Generally, the five-point scale ranges from zero (no impairment) to four (severe impairment) (National Cancer Institute, 1999, 2003). The CSES was completed as part of all questionnaires provided, before, during and six months following chemotherapy treatment. The assessment prior to chemotherapy was to determine a baseline as it was possible some participants would be experiencing the symptoms listed in the scale as a result of recent breast surgery.

6.4 Procedure

Prior to commencement of the study, approval was sought and granted from the relevant ethics committees (Appendix H). To recruit participants, suitable patients were asked whether they would be interested in participating in a study on coping and chemotherapy by their oncologist, breast care nurse or chemotherapy clinic nurse during a routine consultation. Those interested provided oncologists, breast care nurses or nursing staff with permission to pass on their contact details to the investigator. The patient was subsequently contacted by telephone by the investigator to discuss the aim and nature of the study and participation. If the patient chose to participate, an appointment time was made to meet the investigator.

All appointments were conducted in a convenient and private space. Participants were provided with an information sheet and two consent forms, one each for the participant and investigator to keep on file. Two versions of the information sheet (Appendices I and J) and consent form (Appendices K and L) were produced. The first version was given to participants attending The Canberra Hospital, The National Capital Hospital, and the John James Memorial Hospital, and the second version for those attending the Calvary Hospital, as specified by the relevant ethics committees. Following this, the first questionnaire was conducted as a semi-structured interview. This enabled the investigator to build rapport with the participant and show them how to complete the questionnaire. Any questions that arose during this process were addressed.

Given that most appointments were conducted within several days of the first chemotherapy infusion, the participant was provided with the questionnaire to be completed after the first treatment cycle and a replied paid envelope. Participants were instructed to complete the questionnaire one-week following the first treatment cycle

before returning it to the investigator. A telephone call was made in order for the investigator to determine the performance status rating of the participants.

Following the participants' first treatment, the investigator obtained the date and time of their middle treatment cycle appointment from the oncology reception or nursing staff. The investigator met with patients prior to their treatment appointment to provide them with the next questionnaire package. This process was repeated for the final chemotherapy treatment cycle. When the questionnaire was not received within 2 weeks following the first, middle or final treatments, a second questionnaire and replied paid envelope were sent to participants with a letter reminding them to complete and return the questionnaire (Appendix M).

Once chemotherapy was completed, medical data concerning patients' diagnosis and treatment were collected from patients' medical files and results of pathology tests of hepatic and renal functioning were collected from the relevant pathology database by the investigator or participants' oncologist. Six months following the completion of chemotherapy, the follow-up questionnaire and reply-paid envelope were sent to the participants to complete and return to the investigator. Again, when the follow-up questionnaire was not received within 2 weeks, a second questionnaire and replied paid envelope were sent to participants with a letter reminding them to complete and return the questionnaire. (A time-line of the assessment points and contents of the questionnaires is illustrated in Figure 1.)

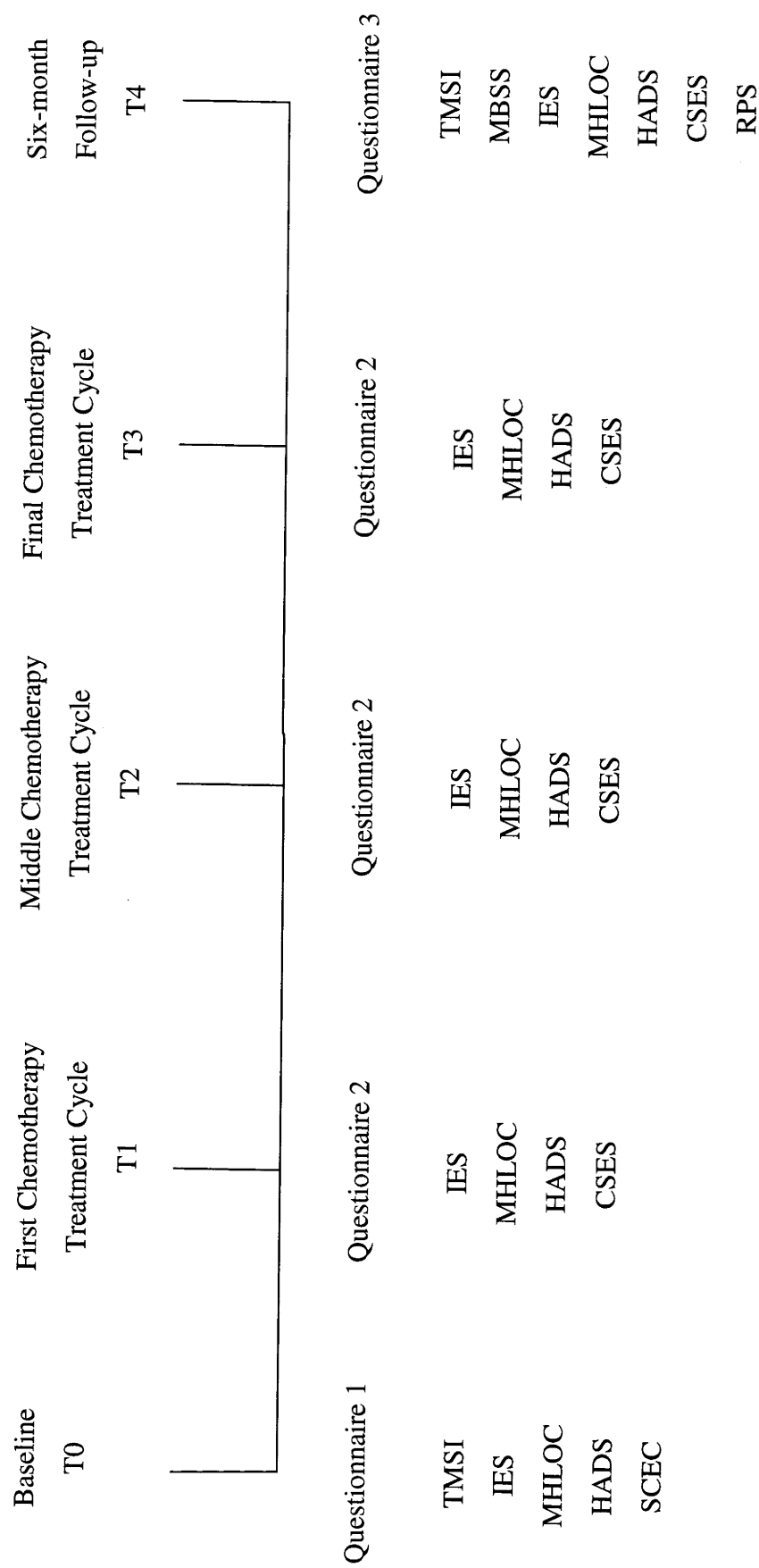


Figure 1. Time-line of assessment points

Note. TMSI (Threatening Medical Situation Inventory), MBSS (Miller Behavioral Style Scale), IES (Impact of Events Scale), MHLOC (Multidimensional Health Locus of Control Scale), HADS (Hospital Anxiety and Depression Scale), CSES (Chemotherapy Side Effects Scale), RPS (Risk Perception Scale).

CHAPTER SEVEN

Results

7.1 Data Analysis

7.1.1 Analysis Plan

The statistical analysis plan aimed to provide insight into the research questions posed. In order to do so, the main aims of the analyses were to investigate:

- 1) the demographic, health, disease and treatment characteristics of the sample (please refer to Chapter 7);
- 2) the extent to which monitoring and blunting coping styles were employed (Chapter 7);
- 3) the reliability and validity of the monitoring and blunting coping styles measure, the Threatening Medical Situations Inventory (Chapter 7);
- 4) the relationships between monitoring and blunting and the levels of anxiety, depression, and side effects (Chapters 8 and 9);
- 5) the relationships between monitoring and blunting and intrusive and avoidant ideation (Chapters 8 and 9);
- 6) the mediating role of intrusive and avoidant ideation in the relationships between monitoring and blunting and the levels of anxiety, depression, and side effects (Chapters 8 and 9);
- 7) the relationships between monitoring and blunting and the locus of control beliefs, internal-, chance-, and powerful others-locus of control beliefs (Chapter 10); and
- 8) the relationships between monitoring and blunting and perceived risks estimated (Chapter 11).

7.1.2 Data Preparation and Screening

All scores were entered and analysed using the Statistical Package for the Social Sciences (SPSS) (SPSS Inc., 2004). Given the small numbers of missing values (less than 5% of values on each variable), the mean substitution method was used for replacement purposes. Scores on the relevant items of the Hospital Anxiety and Depression Scale (HADS; (Zigmond & Snaith, 1983) were reversed. Item scores were summed to calculate the relevant overall and/or subscale scores on the TMSI (van Zuuren & Muris, 1993), MBSS (Miller, 1987), IES (Horowitz et al., 1979); MHLOC (Wallston et al., 1994), HADS (Zigmond & Snaith, 1983), CSES and PRS.

Internal reliabilities were calculated for all of the scales at each time-point measured. Internal reliabilities are presented in Table 1 and most range from adequate to excellent for each of the subscales. Of concern are the lower reliabilities reported for the MHLOC powerful others locus of control subscale and the HADS depression subscale. The low reliabilities were reported at baseline for both subscales and at follow-up for the powerful others locus of control subscale. Item deletion did not improve the reliabilities of any of the subscales.

Table 1
Internal reliabilities of the subscale scores (N=53)

Subscale	Cronbach's α
TMSI	
Monitoring	.84 - .87
Blunting	.70 - .78
MBSS	
Monitoring	.79
Blunting	.73
IES	
Intrusive ideation	.77 - .93
Avoidance ideation	.70 - .89
MHLOC	
Internal	.73 - .86
Chance	.80 - .84
Powerful others	.51 - .79
HADS	
Anxiety	.82 - .90
Depression	.52 - .87
CSES	
Overall	.68 - .79

Inspection of the scale distributions revealed that all subscales were normally distributed. The distributions for anxiety and depression illustrated a slight positive skew and kurtosis at baseline, indicating that most participants reported lower levels of

experience of these constructs. This is not surprising given that participants have not yet started chemotherapy treatment and are therefore unlikely to be highly distressed. For this reason, a decision was made not to transform the variables. A small number of univariate outliers were identified. The univariate outliers were included in the analyses for two reasons: they were deemed to be within the acceptable limits of inclusion (they were around 3 decimal places from the mean) and they were necessary to maintain the moderate size of the sample thus ensuring adequate power of analyses (Tabachnik & Fidell, 2001).

In order to minimise Type I error, Bonferroni adjustments were made when a large number of analyses were conducted on a set of variables. Furthermore, in order to maximise the power of analyses, the number of categories of most of the demographic variables were collapsed into two categories. These variables and their revised categories included marital status (single or partnered), level of education (primary or secondary or tertiary level), employment status (employed or retired) and occupation (non-professionals or professionals). The two marital status categories were formed by combining the single, separated or divorced and widowed categories into one single category and keeping the married/de facto category. The level of education categories were formed by combining the primary school, year 10 and secondary school categories into one primary or secondary category and combining the undergraduate and postgraduate degree categories into one tertiary category.

The employment status categories were formed by deleting the one participant who was unemployed and maintaining those employed and retired participants in separate categories. The occupation categories were formed by combining professionals, associate professionals, and managers and administrators in one professional category and combining tradespersons and related workers, advanced clerical and service workers, intermediate clerical, sales and service workers, intermediate production and transport workers, elementary clerical, sales and service workers, and labourers and related workers into one non-professional category.

Backward elimination regression analyses were conducted to investigate whether monitoring and blunting were significant predictors of anxiety, depression and side effects while accounting for demographic, health, disease and treatment variables. The

benefits of backward elimination regression analysis are two-fold: the method allows easy examination of general trends over time and increased degrees of freedom so a greater number of predictor variables can be included (allowing for more complex explanatory model to be employed). This was important given the exploratory nature of this research. This approach starts with the full model and eliminates the least significant predictors, resulting in a final model that contains only significant predictors. The advantage of this approach is that non-significant predictors do not detract variance away from the significant ones.

The data for each variable from every time-point were pooled into a single variable to create a repeated-measures data set ($N=226$). The regression analyses were conducted using a standard inclusion and exclusion criteria (inclusion criteria $p < .05$, exclusion criteria $p > .051$). Dummy coding was utilised to derive time-point dummy variables to distinguish the between observations made at different time-points. This resulted in five dummy variables which consisted of 0 or 1 (when the observation corresponded to the relevant time-point). Dummy coding was also used to derive a linear trend dummy variable to distinguish the effect of time on the variables investigated. This resulted in one dummy variable which consisted of 0, 1, 2, 3 or 4 (depending on the time-point at which the observation was made). For each backwards elimination regression analysis, time-point variables for T1, T2, T3 and T4 were entered so that the changes in side effects at each time-point were considered according to the baseline levels at T0 (Tabachnik & Fidell, 2001).

For those variables which were consistent across time-points (for example, demographic characteristics), the observations were entered at each time-point. Predictor variables were entered and consisted of two levels. For example, marital status was entered as single (1) or partnered (2). For those variables with more than two levels, each level became a single variable with dummy codes of two levels. For example, method of detection included four levels of self-examination by accident, breast self-examination, clinical examination and routine mammogram. Each method formed a single dependent variable and dummy codes were entered and consisted of no (0) or yes (1). Inspection of the pooled scale distributions for monitoring, blunting, intrusive and avoidant ideation, anxiety, depression and side effects revealed that all scales and subscales were normally distributed (Tabachnik & Fidell, 2001).

Hierarchical regression analyses were conducted to investigate whether monitoring and blunting were significant predictors of perceived risks. Multivariate outlier analysis was conducted. A small number of multivariate outliers were identified. Given the sensitivity of the regression analyses to outliers, they were excluded from the analyses with the use of a $p < .001$ criterion for Mahalanobis distance. Occasions when outliers were excluded from analysis are indicated when relevant (Tabachnik & Fidell, 2001).

7.2 Sample Characteristics

7.2.1 Demographic Characteristics

Descriptive statistics were conducted to investigate the demographic characteristics of participants. Participants' mean age was 52.65 ($SD = 9.33$) years, with a range from 30.16 - 71.26 years. The marital status and state of residence are presented in Table 2. The majority of participants were married or de facto and equivalent amounts were single or separated and/or divorced. Participants resided mainly in the ACT, while the remaining participants lived in the surrounding NSW region.

Table 2
Marital Status, and State of Residence of Participants (N=53)

Variable	<i>f (%)</i>	<i>(n)</i>
Marital status		
Married/de facto	66.0	(35)
Separated/divorced	15.1	(8)
Single	15.1	(8)
Widowed	3.8	(2)
State of residence		
ACT	79.2	(41)
NSW	20.8	(11)

The education and occupational characteristics of participants are presented in Table 3. The majority of participants were highly educated, almost a quarter had completed secondary school and two-thirds had completed a tertiary qualification. Most participants were in full-time employment or retired. Of those employed, the majority were employed full-time. The occupations reflected the high level of education achieved

with the majority working in professional appointments, followed almost equally by associate professional, managerial or administration, and clerical, sales or service positions.

Table 3
Education and Occupation Characteristics of Participants (N=53)

Variable	<i>f (%)</i>	<i>(N)</i>
Education level		
Primary school	3.8	(2)
Year 10	9.4	(5)
Secondary school	24.5	(13)
Undergraduate degree	45.3	(24)
Postgraduate degree	17.0	(9)
Employment status		
Employed	69.8	(37)
Retired	28.3	(15)
Unemployed	1.9	(1)
Employment intensity		
Full-time	81.1	(30)
Part-time	18.9	(7)
Occupation		
Professional	39.6	(21)
Managerial/administration	9.4	(5)
Associate professional	7.5	(4)
Advanced clerical/sales/service	5.7	(3)
Intermediate clerical/sales/service	7.5	(4)

7.2.2 *Health Characteristics*

The methods of detection and referral sources of participants are reported in Table 4. When considering the method of disease detection, over half of participants detected a lump by themselves accidentally. Almost one-fifth of women detected the disease via breast self-examination (BSE) and routine mammogram and only a small number via clinical examination by a general practitioner or other medical professional. The majority of participants were referred to the project by their treating medical oncologist,

with the remaining by either their breast care nurse or chemotherapy nursing staff. All of the 6 medical oncologists approached to act as a referral source to the project agreed. Oncologists referred a mean of 8.83 ($SD=9.50$) participants to the study, with a range of 1 to 27 participants.

Table 4
Methods of Detection and Referral Sources of Participants (N=53)

Variable	<i>f (%)</i>	<i>(n)</i>
Method of detection		
Self examination (accident)	58.5	(31)
Self examination (BSE)	18.9	(10)
Mammogram	17.0	(9)
Clinical examination	5.7	(3)
Referral source		
Oncologist	77.4	(41)
Breast care nurse	13.2	(7)
Hospital nurse	9.4	(5)

Almost two-thirds of participants were public patients (62.3%) and over one-third private (37.7%). Most women attended The Canberra Hospital (34.0%), Calvary Hospital (28.3%) and The National Capital Hospital (28.3%). The remaining few participants attended John James Memorial Hospital (9.4%).

7.2.3 Disease Characteristics

Descriptive statistics were again conducted to investigate the disease characteristics of participants. Participants' number of tumours, tumour grade, number of affected axillary nodes are reported in Table 5. All participants were diagnosed with early breast carcinoma. The overwhelming majority of participants (92.5% or 42 participants) were diagnosed with infiltrating duct carcinoma. Of the remaining forms of EBC diagnosed, infiltrating lobular carcinoma, infiltrating duct and lobular carcinoma, infiltrating pleomorphic carcinoma, and infiltrating micropapillary carcinoma, were each diagnosed in one participant (1.9%). This distribution roughly reflects the histology subtypes of breast cancer cases diagnosed nationally in Australia (AIHW & NBCC, 2006). There was a greater number of participants diagnosed with infiltrating ductal carcinoma

compared to the national rates but this may be due to the inclusion of all cases of breast cancer, early and advanced, in the national rates.

Most participants had one tumour, with a range of 1 to 8 tumours. The mean tumour size was calculated by considering only the largest tumour for those with several tumours, as is usual practice by oncologists (AIHW & NBCC, 2006; Chap et al., 2001a). The mean tumour size was 29.51mm ($SD=16.09$). Most participants were diagnosed with a histological grade of 3. Over two-thirds of participants had evidence of lymph node metastases. The mean number of affected lymph nodes was 6.64 ($SD=7.42$), with a range of 1 to 29. The majority of participants had oestrogen receptor (OR) positive status (64.2%), progesterone receptor (PR) positive status (56.6%) and HER2 receptor negative status (75.5%). Most women were post-menopausal at diagnosis (60.4%) and the remainder were pre-menopausal (39.6%).

Table 5
Tumour characteristics of Participants (N=53)

Variables	<i>f (%)</i>	<i>(n)</i>
Number of tumours		
1	84.9	(45)
2-3	11.4	(6)
>3	3.8	(2)
Tumour grade		
1	1.9	(1)
2	24.5	(13)
3	73.9	(39)
DCIS		
Positive	71.7	(38)
Negative	28.3	(15)
LCIS		
Positive	7.5	(4)
Negative	92.5	(49)
Affected axillary nodes involved		
0	32.1	(17)
1-3	30.2	(15)
4-9	20.8	(11)
>9	17.0	(9)

7.2.4 Surgical Treatment

Descriptive statistics were conducted to determine the characteristics of surgical intervention. All participants received surgical intervention. The majority of participants underwent one surgery (73.6%), although over one-quarter underwent two surgeries (26.4%). The type of surgical intervention received is presented in Table 6. Most participants underwent a unilateral total mastectomy (TM) or breast conserving surgery (BCS). For those undergoing two surgeries, the mean amount of time between procedures was 22.79 (*SD* =9.67) days with a range from 13 to 45 days.

Table 6

Type of Surgical Intervention Received (N=53)

Surgery type	<i>f</i> (%)	(<i>n</i>)
TM	47.2	(25)
BCS	34.0	(18)
BCS plus TM	11.3	(6)
Bilateral TM	7.5	(4)

Note. TM (Total mastectomy), BCS (Breast conserving surgery), BCS plus TM (Breast conserving surgery followed by total mastectomy), Bilateral TM (Bilateral total mastectomy).

7.2.5 Adjuvant Chemotherapy Treatment

On average, chemotherapy commenced with the first infusion 36.34 (*SD* =14.66) days after the final surgery, with a range of 14-92 days. As evident in Table 7, participants were prescribed a range of chemotherapeutic regimens. The most common regimen was FEC which just under half of all participants were prescribed, followed by AC plus Taxol, which around one-quarter were prescribed. Correspondingly, this meant that most participants underwent six treatment cycles (64.2% or 34 participants) while the remaining participants underwent 8 cycles (30.2% or 16 participants) and 4 cycles (5.7% or 3 participants). The majority underwent treatment cycles of 21 days' duration (73.6% or 39 participants) and equal numbers underwent cycles of 28 days' (15.1% or 8 participants) and 14 days' (11.3% or 6 participants) duration. The overwhelming majority of participants were not taking either antidepressants (98.1%) or anxiolytic (96.2%) at diagnosis and throughout chemotherapy.

Table 7
Participants' Prescribed Adjuvant Chemotherapy Treatment Regimens (N=53)

Variables	<i>f (%)</i>	<i>(n)</i>
Chemotherapy Regimen		
FEC	49.1	(26)
Oral CMF	11.3	(6)
AC	7.5	(4)
AC plus Taxol	24.5	(13)
EC plus Taxol	5.7	(3)

Note. FEC (5-fluorouracil, epirubicin, and cyclophosphamide), Oral CMF (cyclophosphamide, methotrexate and 5-fluorouracil), AC (adrimyacin and cyclophosphamide), AC plus Taxol (adrimyacin and cyclophosphamide followed by Taxol), EC plus Taxol (epirubicin and cyclophosphamide followed by Taxol).

The chemotherapeutic drugs received at T1, T2 and T3 are presented in Table 8 and are in line with the regimens prescribed prior to treatment. In line with the prescribed regimens, the majority of participants received FEC followed by AC plus Taxol. T2 was most commonly the third or fourth treatment and T3 was the sixth or eighth treatment received. Small changes in the number of participants receiving the chemotherapeutic drugs at each cycle assessed is due to participants' experience of excessive side effects and therefore the subsequent change to less toxic regimens.

Table 8
Chemotherapeutic Drugs Received at the First, Middle, and Final Chemotherapy Treatments (N=53)

Chemotherapeutic drugs	T1		T2		T3	
	<i>f</i> (%)	(<i>n</i>)	<i>f</i> (%)	(<i>n</i>)	<i>f</i> (%)	(<i>n</i>)
FEC	49.1	(26)	50.9	(27)	45.3	(24)
AC	32.1	(17)	32.1	(17)	11.3	(6)
EC	5.7	(3)	5.7	(3)		
Oral CMF	11.3	(6)	11.3	(6)	13.2	(7)
Taxol					30.2	(16)

Note. FEC (5-fluorouracil, epirubicin, and cyclophosphamide), AC (adrimyacin and cyclophosphamide), EC (epirubicin and cyclophosphamide), Oral CMF (cyclophosphamide, methotrexate and 5-fluorouracil), and Taxol.

The levels of anti-emetic medication prescribed at T1, T2 and T3 are presented in Table 9. The majority of participants received the combination of 5HT₃ agonist and corticosteroid. The numbers of those receiving this level of anti-emetic medication declined over time. A small number of participants switched to the more intensive anti-emetic medication of the combination of 5HT₃ agonist and corticosteroid plus an apprepitant and/or anxiolytic. Others switched to less intensive anti-emetic medication of the single anti-emetic and most likely included those who were prescribed the AC or EC plus Taxol regimen. These participants received AC or EC for T1 and T2, and Taxol for T3. Taxol is considered a less emetogenic chemotherapeutic drug than AC or EC and therefore participants required a less intensive anti-emetic medication at T3.

Table 9
Anti-emetic Medication at the First, Middle, and Final Chemotherapy Treatments
(N=53)

Anti-emetic medication	T1		T2		T3	
	<i>f</i> (%)	(<i>n</i>)	<i>f</i> (%)	(<i>n</i>)	<i>f</i> (%)	(<i>n</i>)
Level 0					9.4	(5)
Level 1	7.5	(4)	7.5	(4)	18.9	(10)
Level 2	84.5	(45)	66.0	(35)	43.4	(23)
Level 3	7.5	(4)	26.4	(14)	28.3	(15)

Participants received additional support during their treatment via the prescription of GCSF support, reduction of chemotherapeutic drug dose, delay of treatment cycle and hospitalisation. GCSF support, dose reductions and treatment delays occurred only at T2 and T3. At T2, almost half of the participants received GCSF support (43.4%) but this declined to around one-third at T3 (34.0%).

A dose reduction was carried out for over one-quarter of participants (26.4%) at T2. The mean reduction from standard dosage was 18.65% (*SD*=9.28), ranging from 5% to 40%. The number receiving a dose reduction increased slightly to almost one-third of participants (32.1%) at T3. The mean dose reduction from standard dosage was 24.17% (*SD*=14.63), ranging from 10% to 55%. At T2, almost one-quarter of participants (18.9%) delayed their treatment a mean of 4.90 (*SD*=2.77) days and a range from 2 to 9 days. After the final treatment, the number declined to just two participants (3.8%) with a mean of 3 days and a range from 1 to 6 days. Treatment delays were all carried out due to excessive side effects from chemotherapy.

A small but considerable number of 6 participants (11.3%) were hospitalised at T1 for neutropenia, fever, dehydration, and cellulitis associated with the surgery wound. Only 2 participants (3.8%) were hospitalised at T2 for fever and haematoemesis due to a Mallory-Weiss tear. An increased number of 6 participants (11.3%) were hospitalised at T3 for neutropenia, tachycardia, dehydration, and thrombosis. It is possible that the number of participants requiring hospitalisation decreased at T2 due to adjustments to the regimens (for example, changes to chemotherapy regimen, dose reductions, and treatment delays) and increases in the anti-emetic and GCSF support provided. The

increase at T3 may be due to an accumulation of toxicity across the treatments, despite the alterations to the treatment provided (Tucker, Chap, & Haskell, 2001).

7.2.6 Radiation Therapy Characteristics

Participants were followed up approximately 6 months post-completion of chemotherapy treatment, with a mean of 194.78 ($SD=33.71$) days post-chemotherapy and a range of 128-272 days. Upon completion of adjuvant chemotherapy, the majority of participants (84.5%) received radiation therapy. On average, participants started radiation therapy 36.14 ($SD=12.27$) days following the final chemotherapy infusion, with a range from 13-76 days. The treatment lasted a mean of 40.44 ($SD=5.94$) days with a range from 21-51 days. On average, participants completed radiation therapy 163.57 ($SD=35.29$) days before the six-month follow-up questionnaire, with a range from 105-259 days.

7.2.7 Endocrine Therapy Characteristics

Following completion of chemotherapy and radiation therapy, the majority of participants (63.2%) commenced endocrine therapy. Of these participants, five years of Tamoxifen was prescribed for almost two-thirds of participants (63.6%), Arimidex for over one-quarter of participants (27.3%), and Zoladex was rarely prescribed (3.0%). The endocrine therapy prescribed was unknown for 2 (6.1%) participants.

7.3 Analysis of Drop-Outs

7.3.1 Demographic Characteristics

Analyses were conducted to determine whether there was a difference in demographic, medical, disease, and treatment characteristics of those participants who completed questionnaires at all time-points and those who failed to complete at least one questionnaire at any of the time-points. A Bonferroni adjustment of $\alpha = .007$ was applied to the results of the analyses of demographic variables. The completers and drop-outs reported similar ages. Completers had a mean age of 53.81 ($SD = 7.82$) years while drop-outs had a mean age of 51.05 ($SD = 11.12$) years. The marital status and state of residence of completers and drop-outs are presented in Table 10. An independent-samples t-test revealed no significant difference in age between completers and drop-outs ($t(51) = 1.08, p > .007$). Chi-square tests revealed no significant

difference between the two groups in marital status ($X^2(1) = .08, p > .007$) and state of residence ($X^2(1) = .09, p > .007$).

Table 10
Demographic Characteristics of Completers (32) and Drop-outs (21)

Variable	Completers		Drop-outs	
	<i>f</i> (%)	(<i>n</i>)	<i>f</i> (%)	(<i>n</i>)
Marital status				
Married/de facto	64.5	(20)	68.2	(15)
Separated/Divorced	12.9	(4)	18.2	(4)
Single	16.1	(5)	13.6	(3)
Widowed	6.5	(2)		
State of residence				
ACT	80.6	(25)	77.3	(17)
NSW	19.4	(6)	22.7	(5)

The educational and occupational characteristics of the completers and drop-outs are presented in Table 11. A series of independent-samples t-tests revealed that there were no significant differences between the two groups in terms of education level ($t(51) = .03, p > .007$), employment status ($t(51) = .35, p > .007$), and employment intensity ($t(37) = .31, p > .007$). A chi-square test of the two groups and occupation type revealed no significant differences for the two groups ($X^2(4) = 4.86, p > .007$).

Table 11
Education and Occupation Characteristics of Completers (N=32) and Drop-outs (N=21)

Variable	Completers		Drop-outs	
	<i>f</i> (%)	(<i>n</i>)	<i>f</i> (%)	(<i>n</i>)
Education level				
Primary school	6.5	(2)		
Year 10	12.9	(4)	4.5	(1)
High School	19.4	(6)	31.8	(7)
University Degree	38.7	(12)	54.5	(12)
Postgraduate Degree	22.6	(7)	9.1	(2)
Employment status				
Employed	74.2	(23)	63.6	(14)
Unemployed			4.5	(1)
Retired	25.8	(8)	31.8	(7)
Employment Intensity				
Full-time	78.3	(18)	85.7	(12)
Part-time	21.7	(5)	14.3	(2)
Occupational				
Professional	21.7	(5)		
Managerial/administration	52.2	(12)	64.3	(9)
Associate professional	13.0	(3)	7.1	(1)
Advanced clerical/sales/service	4.3	(1)	14.3	(2)
Intermediate clerical/sales/service	8.7	(2)	14.3	(2)

7.3.2. *Health Characteristics*

The health characteristics of completers and drop-outs are presented in Table 12. Chi-square analyses were conducted using a Bonferroni adjustment of $\alpha = .017$. The results revealed that there were no significant differences between the two groups on method of detection ($X^2(3) = .92, p > .017$), referral source ($X^2(2) = 3.95, p > .017$) and patient health care status ($X^2(1) = .56, p > .017$).

Table 12
Methods of Detection and Referral Sources of Completers (N=32) and Non-Completers (N=21)

Variable	Completers		Drop-outs	
	<i>f</i> (%)	(<i>n</i>)	<i>f</i> (%)	(<i>n</i>)
Method of Detection				
Self Examination (accidental)	61.3	(19)	54.5	(12)
Self Examination (BSE)	19.4	(6)	18.2	(4)
Clinical Examination	3.2	(1)	9.1	(2)
Routine Mammography	16.1	(5)	18.2	(4)
Referral Source				
Oncologist	71.0	(22)	86.4	(19)
Breast care nurse	12.9	(4)	13.6	(3)
Hospital nurse	16.1	(5)		
Patient Health Care Status				
Public	58.1	(18)	68.2	(15)
Private	41.9	(13)	31.8	(7)

7.3.3 Disease Characteristics

The disease characteristics of completers and drop-outs are presented in Table 13. A series of independent-samples t-test were conducted using a Bonferroni adjustment of $\alpha=.007$. Completers and drop-outs had similar tumour sizes. Completers had a mean tumour size of 1.23mm ($SD = 0.56$) while drop-outs had a mean of 1.59mm ($SD = 1.71$). Menopausal status was somewhat similar, 29.0% of completers were pre-menopausal (9 participants) and 71.0% were post-menopausal While to 54.5% of drop-outs were pre-menopausal and 45.5% were post-menopausal. The results indicated there were no significant differences between the two groups on number of tumours ($t(51) = -1.11, p > .007$), tumour size ($t(51) = -1.36, p > .007$), and the number of affected axillary nodes ($t(51) = -.07, p > .007$). Chi-square analyses revealed no significant differences between the groups on tumour grade ($X^2(2) = .83, p > .007$), DCIS ($X^2(1) = .27, p > .007$), LCIS ($X^2(1) = .67, p > .007$), and menopausal status ($X^2(1) = 3.50, p > .007$).

Table 13

Tumour characteristics of Completers (N=32) and Drop-outs (N=21)

Variables	Completers		Drop-outs	
	<i>f</i> (%)	(<i>n</i>)	<i>f</i> (%)	(<i>n</i>)
Number of tumours				
1	83.9	(26)	86.4	(19)
2-3	16.1	(5)	4.5	(1)
>3			9.0	(2)
Tumour grade				
1	3.2	(1)		
2	22.6	(7)	27.3	(6)
3	74.2	(23)	72.7	(16)
DCIS				
Positive	74.2	(23)	68.2	(15)
Negative	25.8	(8)	31.8	(7)
LCIS				
Positive	9.7	(3)	95.5	(21)
Negative	90.3	(28)	4.5	(1)
Number of affected axillary nodes				
0	38.7	(12)	22.7	(5)
1-3	22.4	(7)	40.5	(9)
4-9	22.4	(7)	18.0	(4)
>9	16.0	(5)	18.0	(4)

7.3.4 Treatment Characteristics

The surgical treatment characteristics of completers and drop-outs are presented in Table 14. A Bonferroni adjustment of $\alpha = .025$ was applied to the analyses of surgical characteristics. Chi-square tests revealed no significant differences in the number of surgeries ($X^2(1) = .26, p > .025$) and the type of surgery performed ($X^2(3) = 7.54, p > .025$).

Table 14
Type of Surgical Intervention Received by Completers (N=32) and Drop-outs (N=21)

Variable	Completers		Drop-outs	
	<i>f</i> (%)	(<i>n</i>)	<i>f</i> (%)	(<i>n</i>)
Number of surgeries				
1	71.0	(22)	77.3	(17)
2	29.0	(9)	22.7	(5)
Surgery type				
TM	51.6	(16)	40.9	(9)
BCS	32.3	(10)	36.4	(8)
BCS plus TM	16.1	(5)	4.5	(1)
Bilateral TM			18.2	(4)

Note. TM (Total mastectomy), BCS (Breast conserving surgery), BCS plus TM (Breast conserving surgery followed by total mastectomy), Bilateral TM (Bilateral total mastectomy).

The chemotherapy treatment regimen of completers and drop-outs are presented in Table 15. Chi-square tests revealed no significant differences in the type of chemotherapy regimen ($X^2(4) = 2.87, p > .05$).

Table 15
Prescribed Adjuvant Chemotherapy Treatment Regimens for Completers (N=32) and Drop-outs (N=21)

Variables	Completers		Drop-outs	
	<i>f</i> (%)	(<i>n</i>)	<i>f</i> (%)	(<i>n</i>)
Chemotherapy Regimen				
FEC	46.9	(15)	57.1	(12)
Oral CMF	15.6	(5)	4.8	(1)
AC	9.4	(3)	4.8	(1)
AC plus Taxol	25.0	(8)	23.8	(5)
EC plus Taxol	3.1	(1)	9.5	(2)

Note. FEC (5-fluorouracil, epirubicin, and cyclophosphamide), Oral CMF (cyclophosphamide, methotrexate and 5-fluorouracil), AC (adrimyacin and cyclophosphamide), AC plus Taxol (adrimyacin and cyclophosphamide followed by Taxol), EC plus Taxol (epirubicin and cyclophosphamide followed by Taxol).

7.3.5 *Clinical Characteristics*

The baseline psychological variables for completers and drop-outs are presented in Table 16. A series of independent-samples t-tests were conducted to determine whether there were any differences in the completers and drop-outs on baseline measures of these psychological variables. A Bonferroni adjustment of $\alpha = .004$ was applied to the results of the analyses of psychological variables. As illustrated in Table 16, there were no significant differences between the two groups on anxiety ($t(51) = .04, p > .004$), depression ($t(51) = -1.34, p > .004$), side effects ($t(51) = -1.84, p > .004$), intrusive ideation ($t(51) = -.63, p > .004$), avoidant ideation ($t(51) = -.91, p > .004$), internal ($t(51) = -1.31, p > .004$), chance ($t(51) = -.08, p > .004$), and powerful others ($t(51) = -1.37, p > .004$) locus of control beliefs and personal ($t(34) = .60, p > .004$), peer ($t(34) = -.24, p > .004$) and comparative ($t(34) = 1.69, p > .004$) perceived risk of recurrence.

Table 16
Baseline Psychological Variables for Completers (N=32) and Drop-outs (N=21)

Variables	Completers		Drop-outs	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Anxiety	4.13	2.70	4.09	4.65
Depression	2.39	1.71	3.45	3.43
Side effects	4.35	2.90	6.27	4.66
Intrusive Ideation	2.84	3.88	13.64	5.36
Avoidant Ideation	10.84	3.68	11.86	4.51
Internal LOC	17.77	5.65	19.82	5.54
Chance LOC	17.56	6.61	17.72	7.34
Powerful Others LOC	26.32	5.37	28.00	3.52
Personal Perceived Risk	4.64	2.21	4.00	2.24
Peer Perceived Risk	4.77	2.00	5.00	1.58
Comparative Perceived Risk	-.13	.95	-1.00	1.73

7.4 *Monitoring and Blunting Coping Styles*

7.4.1 *Monitoring and Blunting Interaction Term*

Before investigating the distribution of monitoring and blunting coping style scores reported, an interaction term was calculated. While high scores on monitoring and blunting indicate the independent use of monitoring and blunting coping styles, an interaction term indicates use of both coping styles. That is, a high score on the interaction term indicates a greater use of both monitoring and blunting and a low score indicates little use of either monitoring or blunting. Middle scores indicate either a moderate use of both monitoring and blunting or greater use of one but not the other. To calculate the interaction term, monitoring and blunting scores were centred by using the following formula; $(X_m - \bar{X}_m) \times (X_b - \bar{X}_b)$, where X_m represents the raw monitoring score, \bar{X}_m the mean monitoring score, X_b the raw blunting score and \bar{X}_b the mean blunting score.

7.4.2 *Monitoring and Blunting Coping*

To investigate participants’ use of monitoring and blunting coping styles, descriptive statistics were calculated for monitoring, blunting and the interaction term scores at T0 and the results are reported in Table 17. At T0, it appears that participants reported

blunting more than monitoring and this was confirmed by a paired-samples t-test ($t(52) = -2.31, p < .025$). Investigation as to whether monitoring and blunting coping were separate dimensions of coping revealed that there was a small, positive but non-significant association between monitoring and blunting scores at T0 ($r = .20, p > .05$).

Table 17
Descriptive Statistics of Monitoring, Blunting and the Interaction Term Scores on the TMSI at T0 (N=53)

Variable	<i>M</i>	<i>SD</i>	Range	Skewness	Kurtosis
Monitoring	40.09	10.68	17 - 60	-.61	-.21
Blunting	44.11	9.30	24 - 59	-.44	-.38
Monitoring-Blunting	19.74	89.60	-238.86 - 255.52	-.16	2.55

Monitoring and blunting were again assessed at T4. The interaction term for these scores was calculated and the descriptive statistics of monitoring, blunting, and the interaction term scores at T4. The results are presented in Table 18 and suggest that participants reported similar levels of monitoring and blunting and this was confirmed by a paired samples t-test ($t(35) = 1.21, p > .05$). Investigation as to whether monitoring and blunting coping at T4 were separate dimensions of coping again revealed that there was little association between monitoring and blunting scores at T4 ($r = .05, p > .05$).

Table 18
Descriptive Statistics of Monitoring, Blunting and the Interaction Term Scores on the TMSI at T4 (N=35)

Variable	<i>M</i>	<i>SD</i>	Range	Skewness	Kurtosis
Monitoring	42.54	8.28	18 - 55	-.85	.96
Blunting	44.54	5.93	32 - 60	.30	.54
Monitoring-Blunting	2.46	34.44	-93.55 - 81.07	-.47	1.53

To investigate the stability of monitoring and blunting coping, Pearson product-moment correlations and paired-samples t-tests were conducted on monitoring, blunting, and the interaction term scores at T0 and T4. Test-retest reliability estimates were moderate for monitoring ($r = .61, p < .05$) and low for blunting ($r = .25, p > .05$) and the interaction

term ($r = .38, p < .05$). Paired-samples t-tests revealed that there was a significant increase in monitoring scores from T0 to T4 ($t(35) = 2.58, p < .05$), but no significant difference in blunting scores ($t(35) = -.78, p > .05$) and the interaction term scores ($t(35) = .76, p > .05$).

Monitoring and blunting were also assessed using the Miller Behavioral Style Scale (MBSS) at T4. The interaction term was again calculated and the descriptive statistics for the monitoring, blunting, and interaction term scores are presented in Table 19. Participants appeared to report the use of more monitoring than blunting on the MBSS and this was confirmed by a paired-samples t-test ($t(19) = 2.70, p < .05$). To investigate whether monitoring and blunting were separate dimensions of coping as measured by the MBSS, a Pearson product-moment correlation showed that there was a small, positive but non-significant association between monitoring and blunting ($r = .27, p > .05$).

Table 19
Descriptive Statistics of Monitoring, Blunting and the Interaction Term Scores on the MBSS at T4 (N=35)

Variable	<i>M</i>	<i>SD</i>	Range	Skewness	Kurtosis
Monitoring	52.90	8.79	31 - 68	-.86	.89
Blunting	46.60	8.45	34 - 60	.94	.31
Monitoring-Blunting	19.26	47.96	-75.50 - 131.40	.59	1.05

To investigate the concurrent validity of the TMSI, the relationships between monitoring and blunting assessed by the TMSI and MBSS were investigated. Pearson product-moment correlations revealed a positive, moderate to strong and significant association between monitoring scores on the TMSI and MBSS at T4 ($r = .75, p < .05$), and positive, small to moderate but non-significant associations between the blunting scores ($r = .40, p > .05$) and interaction scores ($r = .23, p > .05$).

7.4.3 *Monitoring and Blunting Coping and Demographic Characteristics*

To determine whether monitoring and blunting coping are associated with demographic, health, disease and treatment characteristics, a series of analyses were conducted. To investigate the relationships between monitoring and blunting coping and the

demographic characteristics, a Bonferroni adjustment of $\alpha = .007$ was applied to the results of the analyses. Pearson product-moment correlations revealed negative, small and non-significant associations between age and monitoring ($r = -.12, p > .007$), blunting ($r = -.20, p > .007$), and the interaction term ($r = -.05, p > .007$).

Independent-samples t-tests revealed no difference in marital status for monitoring ($t(51) = -1.79, p > .007$), blunting ($t(51) = .71, p > .007$) and the interaction term ($t(51) = -1.17, p > .007$). There was no difference in state of residence for monitoring ($t(51) = 2.72, p > .007$), blunting ($t(51) = 1.85, p > .007$) and the interaction term ($t(51) = 1.26, p > .007$). There was no difference in education level for monitoring ($t(51) = -.15, p > .007$), blunting ($t(51) = .81, p > .007$) and the interaction term ($t(51) = 1.77, p > .007$).

There was no difference in employment status for monitoring ($t(50) = -.07, p > .007$), blunting ($t(50) = .30, p > .007$) and the interaction term ($t(50) = -.20, p > .007$). There was no difference in employment intensity for monitoring ($t(35) = -.22, p > .007$), blunting ($t(35) = -.86, p > .007$) and the interaction term ($t(35) = -2.62, p > .007$). There was no difference in occupational status for monitoring ($t(35) = -.17, p > .007$), blunting ($t(35) = -2.37, p > .007$) and the interaction term ($t(35) = -1.31, p > .007$).

7.4.4 Monitoring and Blunting Coping and Health Characteristics

Analyses were also conducted to investigate the relationships between monitoring, blunting and the interaction term and health variables using a Bonferroni adjustment of $\alpha = .012$. Independent-samples t-tests revealed no significant differences in monitoring ($t(50.96) = .23, p > .012$), blunting ($t(51) = 1.45, p > .012$) and the interaction term ($t(44.16) = .88, p > .012$) according to patient health care status. Levene's test of equality of variances were significant for the t-tests of patient status and monitoring ($F = 5.34, p < .05$) and the interaction term ($F = 6.74, p < .05$) so the t-tests with variance not assumed were considered (Pallant, 2001).

There were no significant differences in monitoring ($t(51) = 1.03, p > .012$), blunting ($t(51) = .95, p > .012$) and interaction term ($t(51) = -.24, p > .012$) scores according to menopausal status. One-way ANOVAs also revealed no significant differences in monitoring ($F(3, 49) = .47, p > .012$ and $F(2, 50) = .35, p > .012$ respectively), blunting ($F(3, 49) = 1.89, p > .012$ and $F(2, 50) = .46, p > .012$) and the interaction

term ($F(3, 49) = 1.63, p > .012$ and $F(2, 50) = .18, p > .012$) according to the method of detection and referral source.

7.4.5 Monitoring and Blunting Coping and Disease Characteristics

Investigation of the differences in disease characteristics according to monitoring, blunting and the interaction term were conducted using a Bonferroni adjustment of $\alpha = .008$. Pearson product-moment correlations revealed no significant differences between number of tumours and tumour size and monitoring ($r = .08, p > .008$ and $r = .05, p > .008$), blunting ($r = -.06, p > .008$ and $r = .29, p > .008$) and the interaction term ($r = .13, p > .008$ and $r = .09, p > .008$). One-way ANOVAs showed no significant differences in monitoring ($F(2, 50) = 1.75, p > .008$), blunting ($F(2, 50) = .87, p > .008$) and the interaction term ($F(2, 50) = 2.00, p > .008$) according to tumour grade.

Independent-samples t-tests revealed no significant differences in the presence of DCIS and LCIS on monitoring ($t(51) = -.66, p > .008$ and $t(51) = -1.77, p > .008$ respectively), blunting ($t(51) = .11, p > .008$ and $t(51) = .52, p > .008$) and the interaction term ($t(51) = -.66, p > .008$ and $t(51) = .45, p > .008$). Pearson product-moment correlations revealed no significant associations between the number of affected axillary lymph nodes and monitoring ($r = .19, p > .008$), blunting ($r = .06, p > .008$) and the interaction term ($r = .04, p > .008$).

7.4.6 Monitoring and Blunting Coping and Treatment Characteristics

Analyses of the differences in treatment characteristics according to monitoring, blunting and the interaction term were conducted using a Bonferroni adjustment of $\alpha = .025$. Independent-samples t-tests revealed no significant differences in monitoring ($t(17.67) = .25, p > .025$), blunting ($t(51) = -.81, p > .025$) and the interaction term ($t(51) = 1.06, p > .025$) according to the number of surgeries undergone. Levene's test of equality of variance was significant for the t-test of the number of surgeries and monitoring ($F = 4.86, p < .05$) so the t-test of equality of variances not assumed was considered (Pallant, 2001). One-way ANOVAs revealed no significant differences in type of surgery and monitoring ($F(3, 49) = 1.41, p > .025$), blunting ($F(3, 49) = 1.25, p > .025$) and the interaction term ($F(3, 49) = 1.16, p > .025$) scores.

7.5 Discussion

The demographic, health, disease, treatment and clinical characteristics of the sample were investigated in order to provide an overall description of the nature of the sample recruited. The results revealed several advantages of the present study compared to those previously conducted. The sample size is similar to those reported in other published prospective studies of women with EBC undergoing treatment (Bishop & Warr, 2003; Jacobsen & Butler, 1996; Lerman et al., 1990; Manne et al., 1994; Shapiro et al., 1997). However, when considering the number of assessment points and the period over which they occur in the present study in comparison to those in the literature, the sample size is considerable.

The present sample was homogenous in terms of demographic, health, disease, treatment and baseline clinical characteristics. The homogeneity in health, disease, treatment and clinical characteristics was no doubt due to the strict inclusion criteria. Most prospective studies include samples that differ significantly in terms of disease, treatment, and to a lesser extent, demographic characteristics (Culver et al., 2002; Epping-Jordan et al., 1999; Hack & Degner, 1999, 2004; McCaul et al., 1999; Osowiecki & Compas, 1999). There was some variation in the sample on specific characteristics but this variation was representative of women diagnosed with EBC in Australia.

Of the demographic and health characteristics, participants reported a wide range of ages, indicative of the full range of ages at which breast cancer is diagnosed in Australian women (AIHW & AACR, 2004, 2006). A number of women in the study lived outside of the ACT, in the surrounding region of NSW, which is indicative of the breast cancer patients treated in the ACT (AIHW & AACR, 2004). Participants reported high levels of education and professional employment, which is in line with the available data of ACT residents (AIHW, 2003).

Participants detected their disease using a range of methods. Fewer participants reported detecting the disease via routine mammogram than the national statistics but this is due to the number of women under the age of 50 years who are not targeted by BreastScreen Australia program (AIHW, 2005). Most participants were referred to the project by their treating oncologist. Oncologists were in the most advantageous position to discuss

research participation because consultations occur immediately prior to chemotherapy treatment and involve discussion of the treatment.

All participants reported similar diagnoses in terms of tumour type, size, grade, axillary node involvement, and presence of DCIS and LCIS, typical of EBC (AIHW, 2006). All treatment was in line with the recommendations for women diagnosed with EBC (NHMRC & NBCC, 2001). The only variation was the time between surgical treatment and the commencement of chemotherapy treatment varied widely. This is perhaps expected given that the interim period involves recovery from surgery, receipt of full diagnosis, and decision-making regarding treatment options, all of which may require significant time (NHMRC & NBCC, 2001).

Interestingly, there were no significant differences between those participants who completed all questionnaires and those who failed to complete at least one questionnaire on any of the demographic, health, disease, surgical treatment, chemotherapy regimen, and baseline clinical characteristics. It might be expected that participants who were more distressed at baseline were less likely to complete all questionnaires. The reason for this is likely due to the homogeneity of the overall sample on these characteristics. This enabled all cases to be included in the analyses.

Of interest was participants' use of monitoring and blunting coping styles. Monitoring and blunting scores were investigated to determine the psychometric properties of the TMSI, participants' use of monitoring and blunting coping styles and the nature of monitoring and blunting coping styles. It was expected that participants used a wide range of monitoring and blunting coping styles, that the TMSI is an acceptable measure of monitoring and blunting coping styles and that monitoring and blunting are mutually exclusive, stable constructs that were unrelated to demographic, health, disease and treatment characteristics.

Participants reported a wide range of use of coping styles on both the TMSI and MBSS scales, although distribution was more restricted on the MBSS scales. The monitoring and blunting coping scores were similar to those reported in other samples, including those at risk of breast, ovarian or cervical cancer (Miller et al., 1999a; Miller, Fang, Manne, Engstrom, & Daly, 1999b; Rees & Bath, 2000; Tercyak et al., 2001) and those

with cancer (Gard et al., 1988; Lerman et al., 1990; Ong et al., 1999; Petersson et al., 2002).

The TMSI appears to be an acceptable measure of monitoring and to a lesser extent, blunting coping. The internal consistencies were excellent for the monitoring subscale and adequate for the blunting subscale. This pattern of internal consistencies is in line with those reported in the literature (van Zuuren et al., 1996; van Zuuren et al., 1999). It has been speculated that the blunting coping style is a more heterogeneous construct than the monitoring coping style (Muris & Schouten, 1994). Therefore, it is possible that the number of blunting coping behaviours included in the TMSI fails to fully capture the construct and results in the low internal consistency.

The test-retest reliabilities of the TMSI coping style scores were moderate for monitoring and low for blunting. The low test-retest reliability of blunting does not fully support the theoretical conceptualisation of blunting as a stable, dispositional attribute (Miller, 1987, 1996; Miller et al., 1993). However, blunting may be a relatively stable attribute but that attribute is not fully captured by the TMSI due to the blunting construct's heterogeneity (Muris & Schouten, 1994), thus test-retest reliability is low. The TMSI and MBSS monitoring and blunting scores were unrelated at baseline and six-month follow-up. This confers with the theoretical conceptualisation of monitoring and blunting as mutually exclusive coping constructs. A lack of association between the coping styles has been consistently reported in the literature (Muris & Schouten, 1994).

The blunting scores were similar at baseline and six-month follow-up, but the monitoring scores were increased at follow-up. Participants were encouraged by medical professionals to monitor their physical wellbeing. Some physical symptoms experienced during chemotherapy indicate conditions that require medical attention. For example, participants are asked to contact the hospital if they develop a fever. A fever during chemotherapy may indicate the body's immune system is compromised, leaving the participant vulnerable to infection (NHMRC & NBCC, 2001). Some participants were even asked to keep a diary of their experience for medical professionals. Participants may have been frequently asked how they are coping with their treatment by family and friends. This may force them to continually reflect on their wellbeing and therefore lead to the increased use of monitoring coping over time.

Monitoring and blunting coping were not associated with any of the demographic, health, disease and treatment characteristics. This confirms the theory that monitoring and blunting coping styles are attributions that are largely independent of personal and situational factors. This is in line with the previous research that suggests the coping styles are unrelated to the situational factors (for example, type of stressful situation – stressful physical or psychological task) (Miller, 1987) and person factors (for example, trait anxiety, hypochondriasis, or medical fears) (Muris et al., 1994d; Steptoe & Noll, 1997; Steptoe & Voegele, 1992).

CHAPTER EIGHT

Monitoring and Blunting Coping Styles and the Experience of Anxiety and Depression

8.1 Anxiety and Depression

8.1.1 Anxiety and Depression Scores

Participants’ experience of anxiety and depression scores were calculated by summary scores of the HADS (Zigmond & Snaith, 1983) subscales. The experiences of anxiety and depression across T0 to T4 were explored. The aim was to determine whether anxiety and depression levels were affected by the monitoring and blunting coping styles. To determine whether monitoring and blunting influenced the experience of anxiety and depression, further analyses were conducted. Descriptive statistics were calculated for anxiety and depression at T0 to T4. The results are presented in Tables 20 and 21 respectively. Consideration of the descriptive statistics shows that anxiety levels fluctuated across time-points while depression levels appear to increase at the start of chemotherapy and decrease following chemotherapy.

Table 20
Descriptive Statistics of Anxiety Scores Across T0-T4

Time-point	<i>N</i>	<i>M</i>	<i>SD</i>	Range	Skewness	Kurtosis
T0	53	4.11	3.60	0-12	1.84	6.10
T1	46	6.09	4.46	0-20	1.29	1.43
T2	47	4.81	3.44	0-13	.62	-.30
T3	44	5.16	4.32	0-20	1.45	2.24
T4	35	3.64	3.51	0-16	1.55	3.27

Table 21
Descriptive Statistics of Depression Scores Across T0-T4

Time-point	<i>N</i>	<i>M</i>	<i>SD</i>	Range	Skewness	Kurtosis
T0	53	2.83	2.59	0-12	1.58	3.37
T1	46	4.50	3.18	0-14	.93	.28
T2	47	5.53	3.59	1-15	.52	-.60
T3	44	5.79	4.24	1-16	.60	-.74
T4	35	2.36	2.67	0-11	1.46	1.82

A series of Pearson product-moment correlations were conducted to investigate the relationships between anxiety scores and depression scores at adjacent time-points. The results for anxiety are presented in Table 22 and show that there were significant, positive, and moderate to strong associations between anxiety scores across T0 to T1. The results for depression are presented in Table 23 and show that there were significant, positive, and moderate to strong associations between depression scores at T1 to T4 but no significant association between scores at T0 and T1.

Table 22
Intercorrelations Between Anxiety Scores Across T0-T4

Time-point	T0	T1	T2	T3	T4
<i>N</i>	53	46	47	44	35
T0	1	.67*	.46*	.52*	.25
T1		1	.74*	.68*	.45
T2			1	.78*	.59*
T3				1	.62*
T4					1

**p* < .05

Table 23
Intercorrelations Between Depression Scores Across T0-T4

Time-point	T0	T1	T2	T3	T4
N	53	47	46	44	35
T0	1	.20	.22	.23	.20
T1		1	.71*	.68*	.32*
T2			1	.64*	.43*
T3				1	.43*
T4					1

* $p < .05$

Comparison of the levels of anxiety and depression at each time-point suggested that more anxiety than depression was reported at T0, T1 and T4. Paired-samples t-tests revealed that there were significantly more anxiety than depression reported at T0 ($t(52) = 2.83, p < .05$), at T1 ($t(52) = 2.74, p < .05$) and at T4 ($t(35) = 3.06, p < .05$) but similar levels of anxiety and depression at T2 ($t(46) = -1.65, p > .05$) and at T3 ($t(43) = -1.17, p > .05$).

Figure 2 presents the mean anxiety scores across T0 to T4 and illustrates that anxiety scores were comparable across T0 to T4. This was confirmed by a non-significant repeated-measures ANOVA ($F(4, 27) = 2.16, p > .05$).

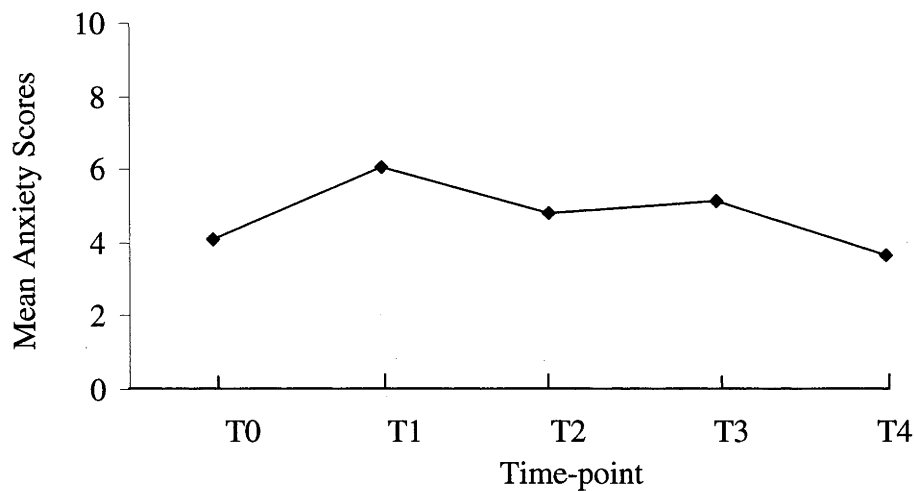


Figure 2. *Mean anxiety scores across T0-T4*

Consideration of the mean depression scores presented in Figure 3 illustrates that there appears to be an increase in scores from T0 to T1, and a decrease from T3 to T4. Given the lack of association between T0 and T1, an independent-samples t-test was conducted to determine if there was a difference in the scores while a repeated-measures ANOVA was conducted to determine if there were differences in scores across T1 to T4. The independent-samples t-test revealed a significant increase in scores from T0 ($M = 2.83$, $SD = 2.59$) to T1 ($M = 4.50$, $SD = 3.18$) ($t(86.85) = -2.83$, $p < .05$). Levene's test of equality of variance was significant ($F = 4.80$, $p < .05$) for the t-test with equality of variances not assumed was considered (Pallant, 2001).

The repeated-measures ANOVA revealed significant differences in scores across T1 to T4 ($F(3, 28) = 8.50$, $p < .05$, partial eta squared = .22). A series of paired-samples t-tests revealed a significant increase in scores from T1 ($M = 4.63$, $SD = 3.24$) to T2 ($M = 5.58$, $SD = 3.55$) ($t(42) = 2.41$, $p < .05$) and a significant decrease from T3 ($M = 4.97$, $SD = 3.86$) to T4 ($M = 2.29$, $SD = 2.60$) ($t(33) = 4.32$, $p < .05$). To determine if there was a significant difference in depression scores at T0 and T4, an independent-samples t-test was conducted and revealed no significant differences ($t(87) = .83$, $p > .05$).

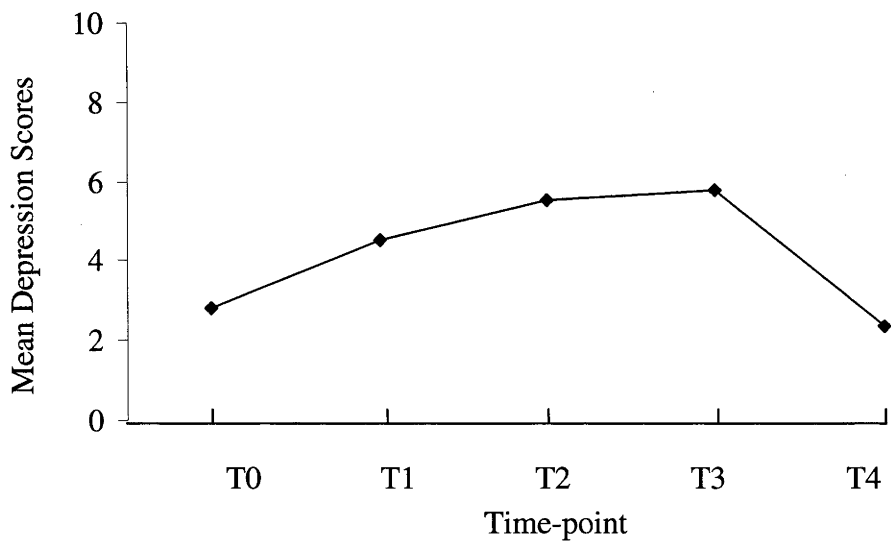


Figure 3. Mean depression scores across T0-T4

To examine the levels of anxiety and depression reported more closely, the frequencies with which the anxiety and depression items were endorsed across T0 to T4 were conducted. The results are presented in Tables 24 and 25 respectively.

Table 24
Frequency (%) of Anxiety Symptoms Reported by Participants Across T0-T4

Symptoms	<i>f</i> (%)				
	T0	T1	T2	T3	T4
<i>N</i>	53	46	47	44	35
Butterflies in stomach	98.1	97.8	100	97.7	27.8
Tension	69.8	80.4	72.3	72.7	63.9
Worrying thoughts	69.8	69.6	59.6	70.5	47.2
Uneasy/not relaxed	30.2	71.7	68.1	70.5	50.0
Restlessness	41.5	71.7	59.6	63.6	52.8
Frightened	41.5	60.9	42.6	36.4	27.8
Panic	24.5	32.6	29.8	36.4	30.6

Table 25
Frequency (%) of Depressive Symptoms Reported by Participants Across T0-T4

Symptoms	<i>f</i> (%)				
	T0	T1	T2	T3	T4
<i>N</i>	53	46	47	44	35
Not cheerful	94.3	100	100	100	16.7
Slowed down	26.4	97.8	100	100	75.0
Not enjoy things used to enjoy	15.1	63.0	78.7	72.7	19.4
Not look forward to things	13.2	39.1	48.9	47.7	19.4
Unable to enjoy TV/radio/book	18.9	30.4	40.4	38.6	19.4
Unable to laugh and see funny side	11.3	26.1	44.7	40.9	13.9
Lost interest in appearance	3.8	28.3	36.2	34.1	13.9

8.1.2 Anxiety and Depression and Demographic Characteristics

A series of analyses were conducted to determine any differences in anxiety and depression according to demographic variables. A Bonferroni adjustment of $\alpha = .008$ was applied to the results of analyses. A Pearson product-moment correlation revealed

there was no significant association between age and anxiety and depression ($r = .04, p > .008$ and $r = .01, p > .008$ respectively). Independent-samples t-tests revealed no significant differences in anxiety and depression according to marital status ($t(51) = -2.26, p > .008$ and $t(51) = -1.23, p > .008$), education level ($t(51) = .68, p > .008$ and $t(51) = .48, p > .008$), employment status ($t(50) = .83, p > .008$ and $t(50) = .12, p > .008$), and employment intensity ($t(35) = .13, p > .008$ and $t(35) = .83, p > .008$) and occupational status ($t(35) = 1.54, p > .008$ and $t(35) = -1.32, p > .008$).

8.1.3 Anxiety and Depression and Health Characteristics

Analyses were also conducted to determine the differences in anxiety and depression according to patient health care status, menopausal status, method of detection and referral source. A Bonferroni adjustment of $\alpha = .025$ was applied to the results of the analyses. Independent-samples t-tests revealed no significant differences in anxiety and depression according to menopausal status ($t(51) = -.65, p > .025$ and $t(51) = .27, p > .025$). One-way ANOVAs indicated no significant differences in anxiety according to method of detection ($F(3, 49) = 1.77, p > .025$ and $F(3, 49) = .65, p > .025$).

8.1.4 Anxiety and Depression and Disease Characteristics

Analyses of the differences in anxiety and depression according to disease characteristics were conducted using a Bonferroni adjustment of $\alpha = .008$. Pearson product-moment correlations revealed no significant associations between anxiety and depression and the number of tumours ($r = -.15, p > .008$ and $r = -.08, p > .008$, respectively), tumour size ($r = .03, p > .008$ and $r = .27, p > .008$) and number of axillary nodes affected ($r = -.13, p > .008$ and $r = .02, p > .008$). A one-way ANOVA revealed no significant differences in anxiety and depression according to tumour grade ($F(2, 50) = 3.10, p > .008$ and $t(50) = .88, p > .008$). Independent-samples t-tests revealed no significant differences in anxiety and depression according to the presence of DCIS ($t(51) = .11, p > .008$ and $t(51) = -.64, p > .008$) and LCIS ($t(51) = -.63, p > .008$ and $t(51) = .66, p > .008$).

8.1.5 Anxiety and Depression and Treatment Characteristics

Investigation of the differences in monitoring, blunting and the interaction term according to treatment variables were conducted using a Bonferroni adjustment of $\alpha = .012$. Pearson product-moment correlations revealed there were no significant

associations between anxiety and depression and the length of time since diagnosis ($r = .03, p > .012$ and $r = .04, p > .012$ respectively) and length of time since final surgery ($r = -.02, p > .012$ and $r = .00, p > .012$). An independent-samples t-test revealed no significant difference in anxiety and depression for the number of surgeries endured ($t(51) = -.29, p > .012$ and $t(51) = -.40, p > .012$). A one-way ANOVA revealed no significant difference in anxiety and depression and type of surgery ($F(3, 49) = 1.15, p > .012$ and $F(3, 49) = .55, p > .012$).

8.2 Intrusive and Avoidant Ideation and Monitoring and Blunting

8.2.1 Intrusive and Avoidance Ideation Scores

Participants' experience of intrusive and avoidant ideation were calculated by summary scores of the IES subscales (Horowitz et al., 1979). In order to investigate the mediating role of intrusive and avoidant ideation in the relationships between monitoring and blunting and anxiety, depression and side effects, a series of analyses were conducted. First, participants' experiences of intrusive and avoidant ideation were examined. Descriptive statistics of intrusive and avoidant ideation were conducted and are presented in Tables 26 and 27.

Table 26
Descriptive Statistics for Intrusive Ideation Across T0-T4

Time-point	<i>N</i>	<i>M</i>	<i>SD</i>	Range	Skewness	Kurtosis
T0	53	7.77	6.71	0-26	.95	.46
T1	46	10.00	7.52	0-32	1.14	1.20
T2	47	9.21	9.08	0-32	.85	-.25
T3	44	10.52	9.81	0-34	.82	-.10
T4	35	7.31	8.55	0-32	1.21	.77

Table 27
Descriptive Statistics for Avoidant Ideation Across T0-T4

Time-point	<i>N</i>	<i>M</i>	<i>SD</i>	Range	Skewness	Kurtosis
T0	53	6.00	5.92	0-28	1.49	2.78
T1	47	9.04	6.89	0-27	.85	.16
T2	46	7.49	6.85	0-27	.68	-.14
T3	44	7.82	7.38	0-27	.75	-.16
T4	35	5.69	5.48	0-19	.70	-.32

Pearson product-moment correlations were conducted to determine the relationships between intrusive and avoidant ideation across T0 to T4. The results reveal that both intrusive and avoidant ideation are significantly, positively, and moderately to strongly associated at T0 ($r = .73, p < .05$ at T0), T1 ($r = .77, p < .05$), T2 ($r = .89, p < .05$), T3 ($r = .89, p < .05$), and T4 ($r = .64, p < .05$).

Pearson product-moment correlations were conducted to determine the association between intrusive and avoidant ideation at each adjacent time-point. The results are presented in Tables 28 and 29, and reveal that intrusive and avoidant ideation are positive, moderately to strongly and significantly associated at T0 to T4.

Table 28
Intercorrelations Between Intrusive Ideation Across T0-T4

	T0	T1	T2	T3	T4
<i>N</i>	53	46	47	44	35
T0	1	.69*	.58*	.72*	.45*
T1		1	.61*	.65*	.54*
T2			1	.67*	.71*
T3				1	.72*
T4					1

* $p < .05$

Table 29
Intercorrelations Between Avoidant Ideation Across T0-T4

	T0	T1	T2	T3	T4
N	53	46	47	44	35
T0	1	.60*	.47*	.59*	.34*
T1		1	.71*	.81*	.52*
T2			1	.67*	.56*
T3				1	.59*
T4					1

* $p < .05$

Repeated-measures ANOVAs were conducted to determine whether intrusive and avoidant ideation changed significantly across T0 to T4. The results revealed that there was a significant change in scores over time for avoidant ideation ($F(4, 27) = 3.32, p < .05$, partial eta squared = .10), but not intrusive ideation ($F(4, 27) = 1.68, p > .05$). Paired-samples t-tests revealed that there were significant increases in avoidant ideation from T0 to T1 ($t(45) = -3.40, p < .05$) and from T1 to T2 ($t(42) = 2.09, p < .05$). Means plots of intrusive and avoidant ideation across the time-points are presented in Figures 4 and 5, respectively.

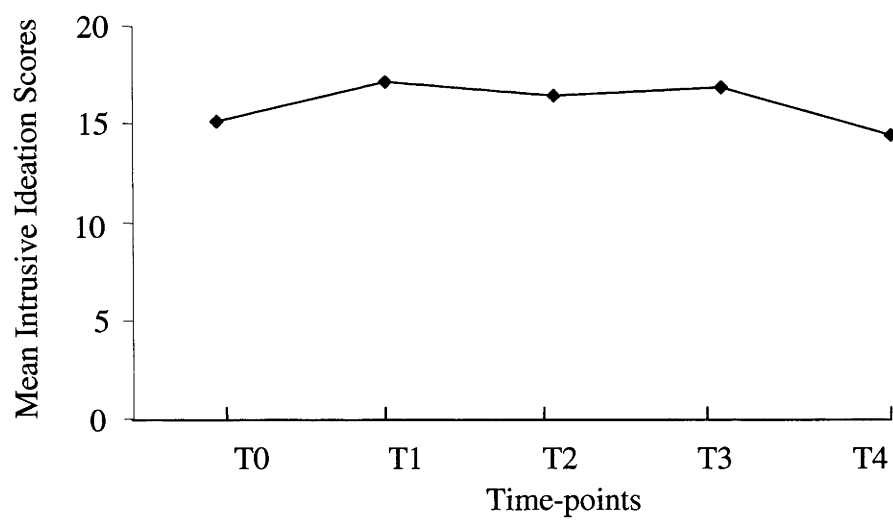


Figure 4. *Mean intrusive ideation scores across T0-T4*

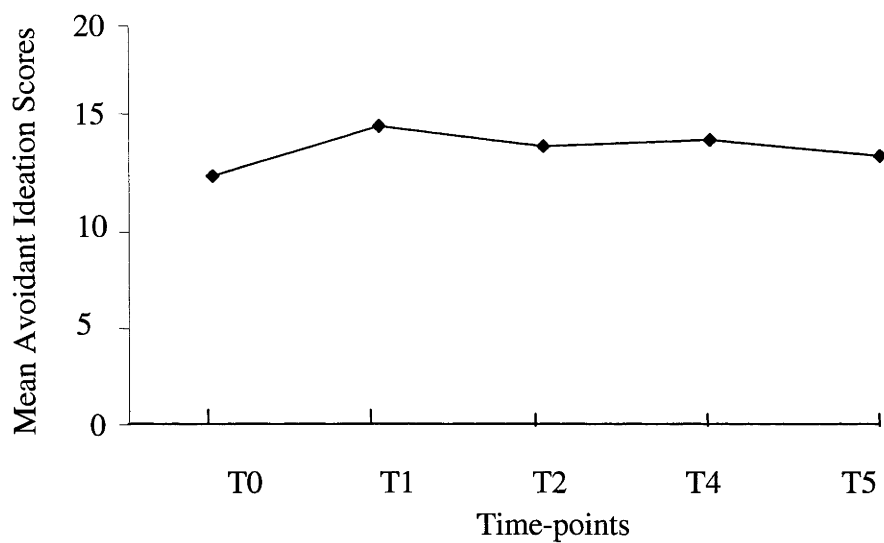


Figure 5. *Mean avoidant ideation scores across T0-T4*

8.2.2 *Intrusive and Avoidant Ideation and Anxiety, Depression and Side Effects*

Pearson product-moment correlations between intrusive and avoidant ideation and anxiety, depression and side effects across T0 to T4 are presented in Table 30. A Bonferroni adjustment of $\alpha = .017$ were applied to the results of the analyses. The results suggest that there are positive, moderate to large and significant associations between intrusive and avoidant ideation and anxiety, depression and side effects.

Table 30
Intercorrelations Between Intrusive and Avoidant Ideation and Anxiety, Depression and Side Effects Across T0-T4

Variables	N	Anxiety	Depression	Side Effects
T0				
Intrusive Ideation	53	.57*	.40*	.26
Avoidant Ideation	53	.55*	.07	.23
T1				
Intrusive Ideation	46	.65*	.30	.31
Avoidant Ideation	46	.67*	.22	.23
T2				
Intrusive Ideation	47	.61*	.47*	.58*
Avoidant Ideation	47	.67*	.47*	.61*
T3				
Intrusive Ideation	44	.78*	.62*	.68*
Avoidant Ideation	44	.77*	.58*	.69*
T4				
Intrusive Ideation	35	.59*	.59*	.74*
Avoidant Ideation	35	.55*	.50*	.66*

* $p < .017$

8.2.3 Intrusive and Avoidant Ideation and Monitoring and Blunting Coping

Next, the relationships between monitoring and blunting coping and intrusive and avoidant ideation were investigated. Pearson product-moment correlations between monitoring, blunting, the interaction term and intrusive and avoidant ideation were conducted using a Bonferroni adjustment of $\alpha = .01$. The results are presented in Table 31 and indicate mainly positive, small to moderate but non-significant associations between the variables.

Table 31

Intercorrelations Between Monitoring, Blunting, the Interaction Term and Intrusive Ideation Across T0-T4

Variables	Intrusive Ideation				
	T0	T1	T2	T3	T4
<i>N</i>	53	46	47	44	35
Monitoring	.29	.25	.33	.33	.36
Blunting	-.01	.33	.25	.20	.34
Monitoring-Blunting	-.02	.08	.12	.02	.24

**p* < .01

Similarly, in order to investigate whether monitoring, blunting, and the interaction term were associated with avoidant ideation, a series of Pearson product-moment correlations were conducted using a Bonferroni adjustment of $\alpha = .01$. The results are presented in Table 32 and indicate mainly positive, small to moderate but non-significant associations between the variables. A positive, moderate and significant association was found between blunting and avoidant ideation at T2.

Table 32

Intercorrelations Between Monitoring, Blunting, the Interaction Term, and Avoidant Ideation Across T0-T4

Variables	Avoidant Ideation				
	T0	T1	T2	T3	T4
<i>N</i>	53	46	47	44	35
Monitoring	.29	.30	.39*	.30	.36
Blunting	-.01	.14	.32	.14	.20
Monitoring-Blunting	-.02	.03	.23	-.03	.03

**p* < .01

8.2.4 Intrusive and Avoidant Ideation and Monitoring and Blunting and Anxiety and Depression

Backwards elimination regression analysis was conducted to determine whether monitoring, blunting, the interaction term, anxiety, depression and side effects were significant predictors of intrusive and avoidant ideation. Intrusive ideation was

investigated in the first regression analysis and was entered as the dependent variable. Monitoring, blunting, the interaction term, avoidant ideation, depression and side effects were entered as predictors. Additionally, demographic, health, and disease and treatment characteristics were included so they were accounted for. The time-line variable and time-point variables for T1, T2, T3 and T4 were entered into the model.

Demographic characteristics included marital status (single or partnered), state of residence (ACT or NSW), level of education (high school or tertiary), employment status (employed or retired), employment intensity (full-time or part-time) and occupation (professional or non-professional). Health characteristics included method of detection (self-examination – accident, self-examination – BSE, clinical examination, or routine mammography), patient status (private or public), and menopausal status (pre-menopausal or post-menopausal).

Disease characteristics included number of tumours, tumour size, tumour grade (1, 2 or 3), number of affected axillary nodes, and presence of DCIS (present or absent) and LCIS (present or absent). Treatment characteristics included number of surgeries, type of surgery (BCS, BCS plus TM, TM, or bilateral TM), performance of axillary lymph node clearance (performed or not performed), radiation therapy (received or not received) and endocrine therapy (received or not received).

The unstandardised regression coefficients (B), the standard error of the regression coefficient (s.e.), standardised regression coefficients (β), and the T test results are presented in Table 33. By design of backward elimination procedures, the overall model is significant ($F(9, 216) = 81.00, p < .001$) and accounts for 76% of variance in intrusive ideation. Of the variables of interest, blunting, avoidant ideation and depression positively predicted intrusive ideation. Participants who reported using more blunting coping and experiencing more avoidant ideation and depression also reported experiencing more intrusive ideation.

Of the demographic and health variables, levels of education negatively predicted intrusive ideation such that participants that were less well educated reported experiencing more intrusive ideation than those who were better educated. Patient health care status and detection of disease via routine mammography positively

predicted intrusive ideation. Participants who had private health care status and detected their disease via routine mammography reported experiencing more intrusive ideation than participants who had public health care status and detected their disease via self-examination (accidental or BSE) and clinical examination.

Of the disease variables, tumour size, tumour grade and the presence of LCIS positively predicted intrusive ideation. Participants who had larger tumours, higher grade tumours and the presence of LCIS compared to those who had smaller tumours, lower grade tumours and the absence of LCIS. Detection of disease via routine mammography and the experience of more avoidant ideation were clearly the two strongest predictors of intrusive ideation.

Table 33
Summary of Backward Elimination Regression Analysis for Variables Predicting Intrusive Ideation (N=226)

Variables	B	s.e.	β	T
Blunting	.12	.03	.14	4.00**
Avoidant ideation	.84	.05	.66	17.40**
Depression	.48	.09	.20	5.50**
Education	-2.43	.60	-.14	-4.02**
Routine mammography	1.79	.75	.82	2.37*
Patient status	1.89	.60	.11	3.12**
Tumour size	.06	.02	.11	3.20**
Tumour grade	1.26	.57	.07	2.20*
LCIS	2.86	1.09	.09	2.63**

Note. $R^2=.77$, $\Delta R^2=.76$

* $p < .05$, ** $p < .05$

Avoidant ideation was entered as the dependent variable. Monitoring, blunting, the interaction term, avoidant ideation, anxiety, depression and side effects were entered as predictors. The demographic, medical, disease and treatment characteristics were also entered. The time-line variables and the time-point variables T1, T2, T3 and T4 were entered into the model.

The results of the regression are presented in Table 34. The model was significant ($F(9, 216) = 70.22, p < .001$) and accounted for 61% of variance in avoidant ideation. The intrusive ideation, anxiety and side effects positively predicted avoidant ideation. The interaction term and depression negatively predicted avoidant ideation. Participants who reported experiencing more intrusive ideation, anxiety and side effects also experienced more avoidant ideation. On the other hand, participants who reported using more of both monitoring and blunting coping and experienced more depression reported experiencing less avoidant ideation.

Of the health variables, detection of the disease via accidental self-examination positively predicted and patient status negatively predicted avoidant ideation. Participants who detected the disease via accidental self-examination and those who had public health care status reported more avoidant ideation. Of the disease and treatment variables, the number of tumours positively predicted and having undergone bilateral TM negatively predicted avoidant ideation. Participants with more tumours and who underwent surgeries other than bilateral TM (BCS, BCS plus TM and TM) reported experiencing more avoidant ideation. Intrusive ideation and anxiety were the strongest predictors of avoidant ideation.

Table 34
Summary of Backward Elimination Regression Analysis for Variables Predicting Avoidant Ideation (N=226)

Variables	B	s.e.	β	T
Monitoring-Blunting	-.01	.00	-.09	-2.43*
Intrusive ideation	.51	.04	.64	13.45**
Anxiety	.52	.08	.31	6.15**
Depression	-.37	.09	-.20	-3.88**
Side effects	.16	.06	.13	2.61**
Self-exam (accidental)	1.29	.48	.10	2.71**
Patient status	-1.39	.49	-.10	-2.85**
Number of tumours	.69	.24	.11	2.86**
Bilateral TM	-2.55	1.18	-.08	-2.17*

Note. $R^2=.74, \Delta R^2=.73$

* $p < .05$, ** $p < .01$

8.3. Anxiety and Monitoring and Blunting

To investigate the relationships between monitoring and blunting coping and anxiety, a series of analyses were conducted. Pearson product-moment correlations using a Bonferroni adjustment of $\alpha = .01$ were conducted to determine the relationships between anxiety and monitoring, blunting and the interaction term. The results are presented in Table 35 and revealed mainly positive, small to moderate but non-significant associations between anxiety and the coping styles.

Table 35
Intercorrelations Between Monitoring, Blunting, the Interaction Term and Anxiety Across T0-T4

Variables	Anxiety				
	T0	T1	T2	T3	T4
<i>N</i>	53	46	47	44	35
Monitoring	.12	.23	.36	.34	.41
Blunting	-.01	.22	.34	.23	.41
Monitoring-Blunting	-.02	.10	.20	.16	.39

* $p < .01$

Next, backward elimination regression analyses were conducted to determine whether monitoring, blunting, the interaction term and intrusive and avoidant ideation significantly predict anxiety and depression. For the first analysis, anxiety was entered as the dependent variable. Monitoring, blunting, the interaction term, intrusive and avoidant ideation, depression and side effects were entered as predictors. Demographic, health, disease and treatment characteristics were included. The time-line variable and time-point variables for T1, T2, T3 and T4 were entered into the model.

The unstandardised regression coefficients (B), the standard error of the regression coefficient (s.e.), standardised regression coefficients (β), and the T test results are presented in Table 36. The model was significant ($F(11, 214) = 36.85, p < .001$) and accounted for 64% of variance in anxiety. Of interest, blunting coping, avoidant ideation and depression positively predicted anxiety. Participants who use more blunting coping and those who experienced more avoidant ideation and depression also

reported experiencing more anxiety. In fact, avoidant ideation and depression were clearly the strongest predictors of anxiety. Of the demographic variables, marital status positively predicted and employment status and occupation negatively predicted anxiety. Participants who were married, were employed and were in professional occupations reported experiencing more anxiety.

Of the treatment variables, the number of surgeries and having undergone axillary clearance negatively predicted anxiety. Having undergone BCS plus TM positively predicted anxiety. Those having undergone one surgery, BCS plus TM surgeries and not undergone axillary clearance reported more anxiety. T2 and T3 positively predicted anxiety such that levels of anxiety at T2 and T3 were higher than expected from the general trend in anxiety.

Table 36

Summary of Backward Elimination Regression Analysis for Variables Predicting Anxiety (N=226)

Variables	B	s.e.	β	T
Blunting	.05	.02	.13	2.92**
Avoidant ideation	.27	.03	.46	10.24**
Depression	.51	.54	.46	9.52**
Marital status	1.76	.36	.21	4.82**
Employment status	-.76	.36	-.09	-2.11*
Occupation	-1.67	.44	-.16	-3.82**
Number of surgeries	-1.21	.49	-.14	-2.46*
BCS plus TM	1.85	.67	.15	2.77**
Axillary clearance	-1.21	.53	-.10	-2.27*
T2	1.12	.42	-.12	-2.68**
T3	-.97	.43	-.10	-2.24*

Note. $R^2=.65$, $\Delta R^2=.64$

* $p < .05$, ** $p < .01$

The results of the above regression analyses provide information about the way in which monitoring and blunting coping styles predict intrusive and avoidant ideation. It is now possible to integrate the findings from all of the regression analyses to determine

the way in which monitoring and blunting and intrusive and avoidant ideation affect the experience of anxiety, depression and side effects across T0 to T4. The model of anxiety is illustrated in Figure 6. The figure shows that the blunting coping style both direct and indirectly via intrusive and avoidant ideation increased anxiety. Only avoidant and not intrusive ideation increased anxiety. As previously mentioned, depression was a significant predictor of anxiety.

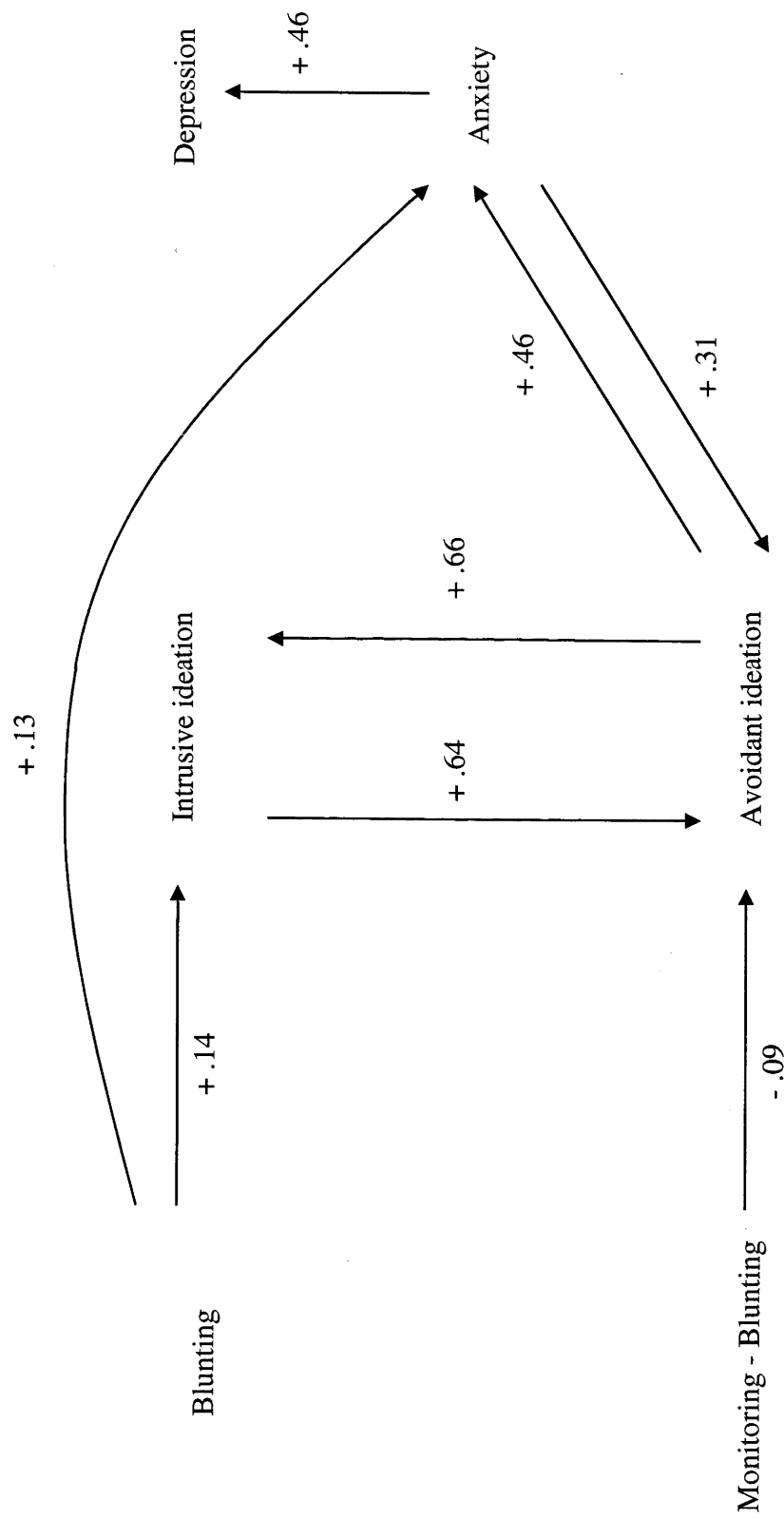


Figure 6. Path model of the influence of monitoring and blunting coping styles on anxiety

8.4. Depression and Monitoring and Blunting

Next, the relationships between depression and monitoring and blunting coping were conducted. Pearson product-moment correlations using a Bonferroni adjustment of $\alpha = .01$ were conducted to determine the relationships between depression and monitoring, blunting and the interaction term. The results are presented in Table 37 and revealed mainly positive, small to moderate but non-significant associations between depression and the coping styles.

Table 37
Intercorrelations Between Monitoring, Blunting, the Interaction Term and Depression Across T0-T4

Variables	Depression				
	T0	T1	T2	T3	T4
<i>N</i>	53	46	47	44	35
Monitoring	.06	.08	.21	.05	.34
Blunting	.10	.06	.13	.17	.40
Monitoring-Blunting	-.02	.19	.10	.08	.35

* $p < .01$

Further analysis was conducted using a backward elimination regression analysis. Depression was entered as the dependent variable. Monitoring, blunting, the interaction term, intrusive and avoidant ideation, anxiety and side effects were entered as predictors. Again, demographic, health, disease and treatment characteristics, the time-line variable and the time-point variables for T1, T2, T3 and T4 were included. The results of the analysis are presented in Table 38. By design of backward elimination regression analysis, the model of depression was significant ($F(13, 212) = 28.92, p < .001$) and accounted for 62% of variance. Intrusive and avoidant ideation, anxiety and side effects positively predicted depression. Participants who reported experiencing more intrusive and avoidant ideation, anxiety and side effects also reported experiencing more depression.

Of the demographic and health variables, age and state of residence positively predicted depression while marital status and patient health care status negatively predicted depression. Participants who were older, single, lived in the ACT and had public health care status reported more depression than those who were younger, married, lived in

surrounding NSW and had private health care status. Of the disease and treatment predictors, tumour grade, presence of DCIS and number of surgeries negatively predicted depression. Participants who had a low grade of tumour, no evidence of DCIS and underwent two surgeries reported more depression than those who had a high grade of tumour, presence of DCIS and underwent one surgery. T2 and T3 positively predicted depression such that levels of depression were higher at T2 and T3 compared to the general trend in depression.

Table 38
Summary of Backward Elimination Regression Analysis for Variables Predicting Depression (N=226)

Variables	B	s.e.	β	T
Intrusive ideation	.09	.03	.22	2.85**
Avoidant ideation	-.16	.04	-.30	-3.94**
Anxiety	.37	.06	.41	6.61**
Side effects	.27	.04	.42	7.28**
Age	.05	.02	.14	3.19**
State of residence	1.02	.39	.12	2.61**
Marital status	-.76	.34	-.10	-2.21*
Patient status	-1.38	.31	-.19	-4.38**
Tumour grade	-.71	.33	-.10	-2.19*
DCIS	-1.19	.38	-.15	-3.17**
Number of surgeries	.90	.37	.11	2.45*
T2	1.22	.39	.14	3.13**
T3	1.82	.40	.13	2.92**

Note. $R^2=.64$, $\Delta R^2=.62$

* $p < .05$, ** $p < .01$

Figure 7 illustrates the model of depression. Depression was indirectly influenced by the use of blunting and the use of neither monitoring nor blunting via intrusive and avoidant ideation. Intrusive ideation increased depression but avoidant ideation reduced depression. An inspection of the beta weights suggested that the strength of the associations between intrusive ideation and depression, and avoidant ideation and depression, were similar. Both side effects and anxiety increased depression.

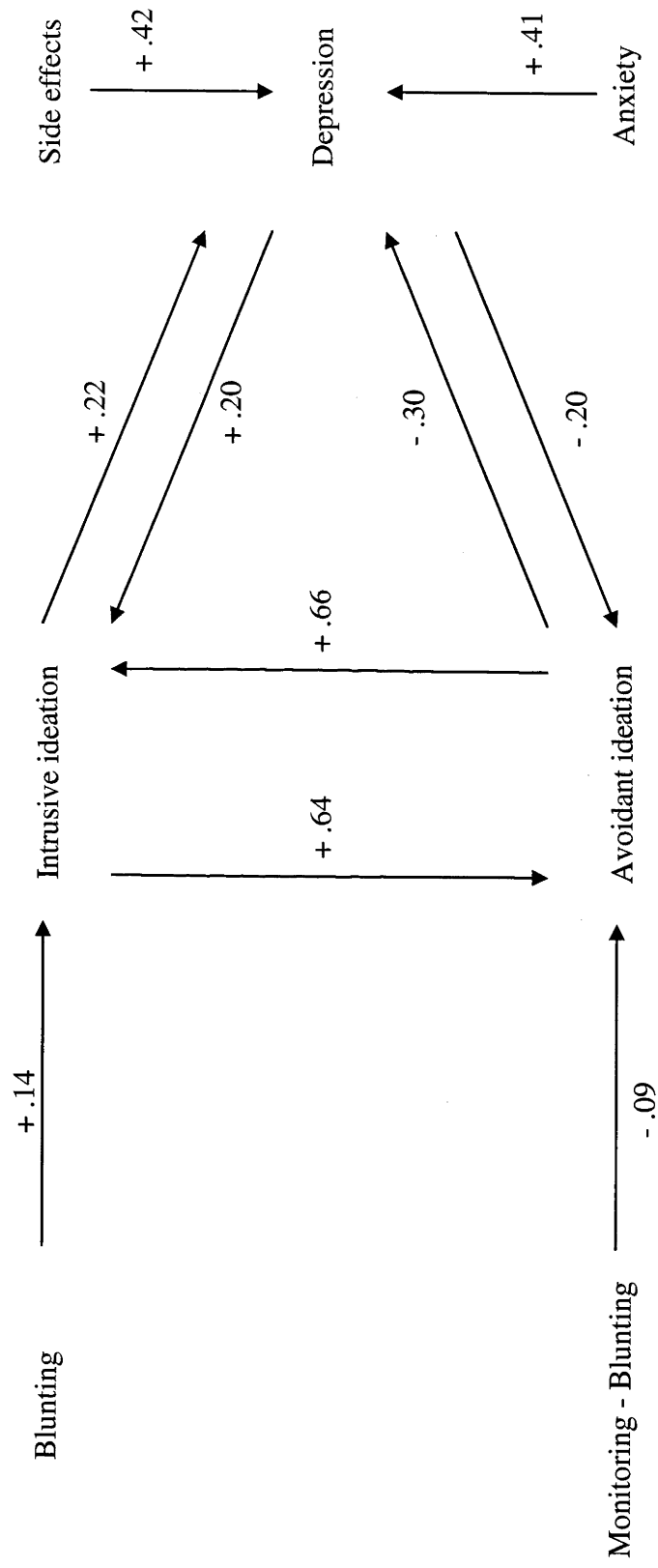


Figure 7. Path model of the influence of monitoring and blunting coping styles on depression

8.5 Discussion

The experience of anxiety and depression before, during and following chemotherapy treatment was investigated. Participants reported a broad range of anxiety and depression experienced at baseline, during treatment and at follow-up. The mean levels of anxiety and depression reported are equivalent to that reported in other samples of women undergoing treatment for breast cancer (Alder & Bitzer, 2003; Groenvold et al., 1999; Mathews, Ridgeway, Warren, & Britton, 2002; Montazeri et al., 2000; Morasso et al., 2001; Osborne et al., 2004; Osborne et al., 2003; Payne et al., 1999; Rodgers et al., 2005).

Mean anxiety levels remained relatively stable over time with decreases after the middle and final chemotherapy treatments. Few studies have investigated levels of anxiety across chemotherapy treatments, instead investigating general distress during a limited period of time. These studies suggest distress remains relatively stable (McKinnon, 2001; (Lerman et al., 1990; Manne et al., 1994; Shapiro et al., 1997) although patients experience some significant concerns at the beginning of treatment. Patients report that they have significant concerns about the challenging nature of chemotherapy prior to commencement and are eager to start chemotherapy to see what it involves (Moyer & Salovey, 1996). These concerns were reflected in the remarks from participants at the baseline interview. Many participants made comments similar to the following, "I just want to get the first one over so I know what I'm in for" and "I'll feel better after the first one". Therefore it is understandable that anxiety would be elevated prior to and during the first treatment but would decline as participants became familiar with the treatment and its effects.

On the other hand, depression levels increased during treatment and in particular, after the middle and final treatments. Again, past research has typically investigated general distress during a limited period of chemotherapy treatment and has suggested distress levels were stable (Lerman et al., 1990; Manne et al., 1994; McKinnon, 2001; Shapiro et al., 1997). No research has indicated that levels of distress increase during treatment, although this pattern of depression is perhaps understandable. Once participants are aware of what chemotherapy and its effects involve, they then have to adjust to dealing with the treatment for the remainder of the treatment. Patients may find this period long, difficult and exhausting, resulting in the experience of depression. As one participant succinctly said, "It got to be quite a grind." Another explained, "I started off my chemo

ride full of hope for a speedy and problem free experience. As I proceeded through my treatment my resolve started to wain.”

At six-month follow-up, anxiety and depression levels were similar to those reported at baseline. That is, anxiety levels were maintained whereas depression levels declined from those experienced during chemotherapy. This is understandable when considering that the six-month follow-up coincided with the first few months of survival. Perhaps when participants finish their treatments and are able to return to the routine of their daily lives, their depression levels decline. Participants commented, “I feel like my old self again”, “I am feeling better and back to normal” and “I am enjoying life, relationships, friends etc. as much as I ever did before my diagnosis”.

Alternatively, their anxiety levels may be maintained due to the significant concerns reported during early survivorship. Past research has shown that when patients are no longer undergoing active treatment, they feel a loss of support from medical professionals, family and friends. In the present study, participants did report that they felt disconnected after completion of treatment. One participant went as far to say that she was “disappointed with post-care” while another felt that “some follow-up counselling would be in order – not just physical checks about recurrence”. This is compounded by concerns about recurrence, especially given that active treatment is completed and there is little to do but anticipate the next check-up. One participant said that although they felt positive, “from time to time I worry about it coming back”. Another commented on occasionally experiencing the “‘patient’ feeling of the last years and the uncertainty of good health”.

The patterns of anxiety and depression symptoms reported were similar across all time-points. The overwhelming majority of participants reported experiencing the anxiety of butterflies in the stomach, tension and worrying thoughts and the depression symptoms of not feeling cheerful and having slowed down. The least experienced anxiety symptom was panic while the least experienced depressive symptoms were unable to laugh and see the funny side of things and having lost interest in one’s appearance. The fact that a loss of interest in appearance was one of the least common symptoms is surprising. Body image problems have been widely reported by patients following breast surgery (Abend & Williamson, 2002; Al-Ghazal et al., 2000; Arora et al., 2001;

Curran et al., 1998; Hartl et al., 2003; Hopwood et al., 2001). Perhaps body image concerns are better reflected as concern about appearance rather than a lack of interest in it. Nevertheless, the least experienced symptoms were still experienced by significant number of participants.

There is the possibility that the levels of depression reported are an underestimation of participants' actual experience of depression. Concern exists regarding the validity of the HADS in assessing depressive symptoms. The HADS depression items appear to overwhelming focus on symptoms indicative of anhedonia. This is to the exclusion of other symptoms of depression such as indecisiveness, guilt, helplessness, worthlessness and suicidality (Love et al., 2002; Osborne et al., 2004). Evidence supporting these concerns comes from research showing that the HADS underestimates depression levels in breast cancer patients compared to other, more comprehensive, depression scales (Hall et al., 1999; Love et al., 2002).

In addition, it is concerning that one of the most common depression symptoms reported was having slowed down. Most participants commented that they had slowed down due to the side effects experienced from chemotherapy treatment, rather than as a reflection of their mental wellbeing. The item of feeling slowed down may therefore be an inappropriate indicator of depression in breast cancer patients undergoing chemotherapy treatment. A reliable and valid measure of anxiety and depression in cancer patients is vital for future research in the field and according to some, is long overdue (Hall et al., 1999).

Monitoring and blunting coping styles played significant roles in the experience of anxiety and depression, although not in the ways expected. Miller's (1996; 1993) theory states that the use of monitoring coping is associated with increased levels of anxiety and depression while the use of blunting coping is associated with reduced levels of distress. This has been supported by empirical research indicating that monitoring is associated with greater levels of distress than blunting coping (Lerman et al., 1990; Miller, 1979b; Miller et al., 1996a; Miller et al., 1995; Muris & de Jong, 1993; Schwartz et al., 1995; Tercyak et al., 2001; van Zuuren, 1993).

Miller's (1996; 1993) theory also states that the influence of coping styles is mediated by the experience of increased levels of intrusive and avoidant ideation, which in turn, increase levels of anxiety and depression. This too has been supported in the past research (Devine et al., 2003; Manne et al., 2001). Finally, Miller's theory suggests that anxiety and depression in turn increase levels of intrusive and avoidant ideation although this has not been investigated in studies of coping, intrusive and avoidant ideation and psychological and physical wellbeing.

The findings partially support Miller's (1996; 1993) theory and the past research. The use of blunting and the use of both monitoring and blunting increased levels of anxiety indirectly via the experience of increased intrusive and avoidant ideation. Intrusive and avoidant ideation appeared to have a reciprocal relationship in which each served to increase levels of the other. Avoidant ideation then increased levels of anxiety and in turn, anxiety was found to increase avoidant ideation. Anxiety levels were also directly increased by the use of blunting coping.

Similar results were reported for depression whereby the use of blunting increased depression indirectly, via the experience of intrusive and avoidant ideation. The use of blunting increased intrusive ideation while the use of both monitoring and blunting reduced the levels of avoidant ideation. As stated, intrusive and avoidant ideation both increased levels of each other. Intrusive ideation then increased depression and in turn, depression increased intrusive ideation. On the other hand, avoidant ideation reduced levels of depression and depression reduced levels of avoidant ideation. That is, the coping styles were able to increase depression via intrusive ideation and reduce depression via avoidant ideation. Inspection of the beta weights in both paths revealed that the strength of the relationships between coping styles and intrusive and avoidant ideation, and intrusive and avoidant ideation and depression were similar. This suggests that overall changes in levels of depression via coping styles were minimal.

Although the finding is contrary to Miller's (1996; 1993) theory, Horowitz's (1993; 1979) and Miller's theories may provide a possible reason why participants' use of blunting increased intrusive ideation. According to the theories, failure to engage with the information about a stressful situation means the situation is not processed or adjusted to. Intrusive and avoidant ideation occur in order to facilitate engagement with

the stressful situation and therefore encourage the processing of and adjustment to the situation. When using blunting coping, people avoid or escape information regarding the stressful situation. That is, they do not engage with the information and therefore are unable to process and adjust to the situation. Intrusive ideation may then occur to help facilitate this process of adjustment.

Miller's (1996; 1993) theory also provides a reason why participants' use of blunting directly increased anxiety levels. It is also possible that participants using blunting coping knew less about treatment. Therefore, they may have experienced more anxiety because they were uncertain about what to expect of the treatment and/or they were ill-prepared to deal with the treatment. As one participant commented, "being given information about my diagnosis and treatment...made it easier to understand what to expect." Although the results do not confirm past research of monitoring and blunting coping styles, research investigating the related construct of avoidance coping strategies has suggested these strategies are associated with more psychological distress in breast cancer patients (Carver et al., 1993; Culver et al., 2002; Epping-Jordan et al., 1999; Friedman et al., 1988; Hack & Degner, 1999, 2004).

The reasons why participants' use of both monitoring and blunting were associated with reduced levels of avoidant ideation. Miller's (1996; 1993) theory provides no description of the nature and effects of this form of coping, although attempts have been made by Krohne (Krohne, 1993). According to Krohne, people using both monitoring and blunting coping are intolerant of both the uncertainty and emotional arousal elicited by stressful situations. They employ monitoring because it serves to reduce uncertainty and they employ blunting because it serves to reduce emotional arousal. The intolerance of both uncertainty and emotional arousal experienced means that distress is high in stressful situations. In an effort to reduce distress, they continually switch between the coping styles in order to reduce distress. Unfortunately, this allows insufficient time for either coping style to be effective, resulting in high levels of distress. As a result, Krohne has labelled these people as 'ineffective copers'. It is possible that this continual switching provides little opportunity for people to engage in avoidant ideation.

The results then show that avoidant ideation decreases depression and depression in turn reduces avoidant ideation. Although this is contrary to Miller's (1996; 1993) theory,

Horowitz's (1993; 1979) and Miller's theories do provide possible explanations for the results. Avoidant ideation involves avoidance of intrusive ideation about stressful situations, in order to reduce distress. Therefore, it is likely that avoiding intrusive ideation would reduce depression levels.

When considering the finding that depression reduces avoidant ideation, it may be hypothesised that depression inhibits people's ability to engage in avoidant ideation. Depression symptoms involve reduced concentration and increased helplessness and hopelessness (American Psychiatric Association, 1994), all of which make it less likely that participants are able to actively engage in strategies to reduce distress, such as avoidant ideation. Clearly, further investigation is needed to delineate the mechanisms underlying the pattern of results obtained.

Anxiety and depression were found to be significant predictors of each other. This confirms a large body of empirical evidence demonstrating a strong relationship between anxiety and depression (Barlow & et al., 1986). Indeed, there is suggestion that anxiety and depression represent the same response at a biological level (Middeldorp, Cath, Van Dyck, & Boomsma, 2005). Side effects also increased depression levels but not anxiety levels. Anxiety results from concerns about future negative events (American Psychiatric Association, 1994). While participants may experience anxiety in anticipation of side effects, they would be unlikely to do so once they have developed the side effects. Instead, the experience of side effects might make participants feel depressed because they weren't able to prevent the side effects and the side effects negatively affect quality of life.

Aside from the influence of monitoring and blunting coping styles, marital status and employment was shown to be the only background characteristics to consistently affect levels of anxiety and/or depression. Single participants reported significantly less anxiety than partnered participants. This is contrary to past research which has suggested that being partnered acts as a protective factor against elevated levels of psychological distress in patients with breast cancer (Compas et al., 1999; Epping-Jordan et al., 1999; Osborne et al., 2003; Turner et al., 2005). Although, it should be noted that having a partner does not necessarily mean that people experienced enhanced support.

Nonetheless, it is possible that partnered participants not only have a partner but also may be more likely to have children and therefore greater family responsibilities. Partnered participants may be worried about their ability to cope with these responsibilities when undergoing treatment and about how these responsibilities will be met if they do not survive the disease. Being surrounded by family may also lead to frequent enquiries about participants' wellbeing, which may serve to highlight participants' declines in wellbeing and therefore raise anxiety.

It has been suggested that there may also be secondary gains for partnered women experiencing distress. Secondary gain has not previously been discussed in the cancer research but is evident in the research on patients with chronic pain (Fishbain, Rosomoff, Cutler, & Rosomoff, 1995). That is, partnered women may receive a number of benefits in their relationships with their partners when they are unwell. Alternatively, single women do not experience such benefits and may be unlikely to dwell on worries. One participant reported that going through the experience as a "single woman living alone...has made me a stronger person."

In contrast, single participants reported more depression than partnered participants. This result confirms past research that suggests single women experience more psychological distress than partnered women when receiving and undergoing treatment for breast cancer (Compas et al., 1999; Epping-Jordan et al., 1999; Osborne et al., 2003; Turner et al., 2005). It is thought that partners offer support that buffers the woman from stress and therefore may serve to lower the likelihood of experiencing depression (de Groot, 2002). It is also possible that partnered participants have more family responsibilities than single participants. While these responsibilities may cause significant anxiety, they may form as a distraction which prevents women from reflecting on their disease and treatment and developing depression.

Participants who were employed or employed in professional occupations reported more anxiety than those who were retired or employed in non-professional occupations. It is possible that participants who have the responsibility of work, particularly professional work, might find it difficult to take time off work for treatment and recovery and/or to cope with work while undergoing treatment. As one participant explained, "I pushed myself to work normally". Taking time off work may also result in

a loss of income that significantly affects participants' abilities to meet financial responsibilities. It may also be that participants in professional occupations may be used to feeling in control and successful in their work and when faced with a new and largely uncontrollable situation, they experience greater anxiety.

To a lesser extent, disease and treatment characteristics affected levels of anxiety and depression although the individual characteristics did not consistently affect anxiety and depression in the same manner. When considering the characteristics as a whole, it may be said that participants who underwent less extensive the surgical intervention (one surgery compared to two and no axillary clearance) reported more anxiety than those undergoing more extensive surgical intervention (two surgeries and axillary clearance). It is possible that participants receiving less extensive treatment are concerned that not all cancer cells have been removed and therefore, the disease will return. Indeed, it has been suggested that participants' perceptions of risk regarding cancer is unrelated to objective indices of disease and are instead based on psychological factors (Kent et al., 2000).

Alternatively, participants diagnosed with less extensive disease (low tumour grade and no evidence of DCIS) and those participants who underwent more treatment (two rather than one surgery) reported more depression. Participants with less extensive disease may have had fewer symptoms upon diagnosis than those with more extensive disease and therefore may have been unprepared for the diagnosis of cancer. This may lead to the experience of depression as participants struggle to adjust to the diagnosis. Participants who underwent more treatment may be more resigned to the disease and its treatment and therefore feel more depressed than those who underwent less extensive surgery.

Overall, the results of the levels of anxiety and depression has provided an intensive examination of psychological distress experienced before, during and following chemotherapy treatment for EBC. The results indicate that the patterns of anxiety and depression levels over time differed considerably. As expected, monitoring and blunting coping styles accounted for a significant amount of the variation in anxiety and depression scores reported, although not in the ways predicted by Miller's (1996; 1993) theory and past research.

CHAPTER NINE

Monitoring and Blunting Coping Styles and the Experience of Side Effects

9.1. Side Effects

9.1.1. Side Effect Scores

Participants’ experience of overall side effects was calculated from the summary score of the Chemotherapy Side Effects Scale, developed for use in the present study. The experience of side effects across T0 to T4 were investigated with the aim of determining whether the experience of side effects are affected by the monitoring and blunting coping styles. To investigate the relationships between monitoring and blunting and side effects, a series of analyses were conducted. Descriptive statistics for side effects scores across T0 to T4 were calculated and are presented in Table 39. The descriptive statistics indicate that participants reported a wide range of overall side effects but generally, mean side effects increased during chemotherapy treatment.

Table 39
Descriptive Statistics of Side Effects Scores Across T0-T4

Time-point	<i>N</i>	<i>M</i>	<i>SD</i>	Range	Skewness	Kurtosis
T0	53	5.15	3.81	0-16	1.12	1.19
T1	46	10.22	4.66	2-24	.80	1.13
T2	47	10.34	4.99	3-22	.62	-.58
T3	44	10.77	5.84	3-33	1.58	4.14
T4	35	5.34	4.69	0-22	1.70	3.69

The frequency with which side effects were reported across T0 to T4 are reported in Table 40. Many participants reported experiencing a number of side effects prior to the beginning of chemotherapy treatment. The most common side effects experienced at T0 were pain, difficulty sleeping, fatigue and sore muscles. Most of the side effects increased at the beginning of treatment and declined after the completion of treatment. Several of these side effects did not return to similar levels as thought at T0 but instead remained elevated. These side effects included fatigue, memory problems, shortness of breath and coughing.

Table 40
Frequency (%) of Side Effects Reported by Participants Across T0-T4

Side Effects	<i>f (%)</i>				
	T0	T1	T2	T3	T4
<i>N</i>	53	46	47	44	35
Fatigue	50.9	100	100	97.7	65.7
Difficulty Sleeping	52.8	73.9	78.7	75.0	57.1
Nausea	24.5	82.6	72.3	56.8	14.3
Lack of Appetite	30.2	77.8	68.1	63.6	17.1
Pain	62.3	43.5	63.8	56.8	45.7
Sore Muscles	50.9	42.2	58.7	65.9	45.7
Memory Problems	22.6	40.0	67.4	72.7	54.3
Constipation	26.4	69.6	57.4	47.7	8.6
Coughing	20.8	15.6	34.8	34.1	31.4
Dizziness	18.9	37.8	32.6	34.1	5.7
Shortness of Breath	5.7	21.7	19.6	29.5	22.9
Vomiting	1.9	32.6	17.4	18.2	2.9

Pearson product-moment correlations indicated that there were significant, positive and moderate to strong associations between side effects scores across T1 to T4, but not between T0 and T1. The results are presented in Table 41.

Table 41
Intercorrelations Between Side Effects Across T0-T4

Time-point	T0	T1	T2	T3	T4
<i>N</i>	53	46	47	44	35
T0	1	.28	.28	.29	.17
T1		1	.50*	.60*	.42*
T2			1	.71*	.36*
T3				1	.58*
T4					1

**p* < .05

Examination of the mean side effects scores across T0 to T4 in Figure 8 suggests an increase in side effects from T0 to T1 and a decrease from T3 to T4. Again, given the lack of association between scores at T0 and T1, an independent-samples t-test was conducted to determine whether there was a difference in scores between T0 and T1 and a repeated-measures ANOVA was conducted on scores from T1 to T4. The independent-samples t-test indicated that there was a significant increase from T0 ($M = 5.15$, $SD = 3.81$) to T1 ($M = 10.22$, $SD = 4.66$) ($t(95) = 5.82$, $p < .05$). The repeated-measures ANOVA showed that there were significant differences in scores across T1 to T4 ($F(4, 27) = 17.75$, $p < .05$, partial eta squared = .37). A series of paired-samples t-tests revealed a significant decrease from T3 ($M = 9.65$, $SD = 4.47$) to T4 ($M = 4.92$, $SD = 3.82$) ($t(33) = 7.17$, $p < .05$). An independent-samples t-test of side effects at T0 and T4 revealed no significant differences ($t(87) = -.21$, $p > .05$).

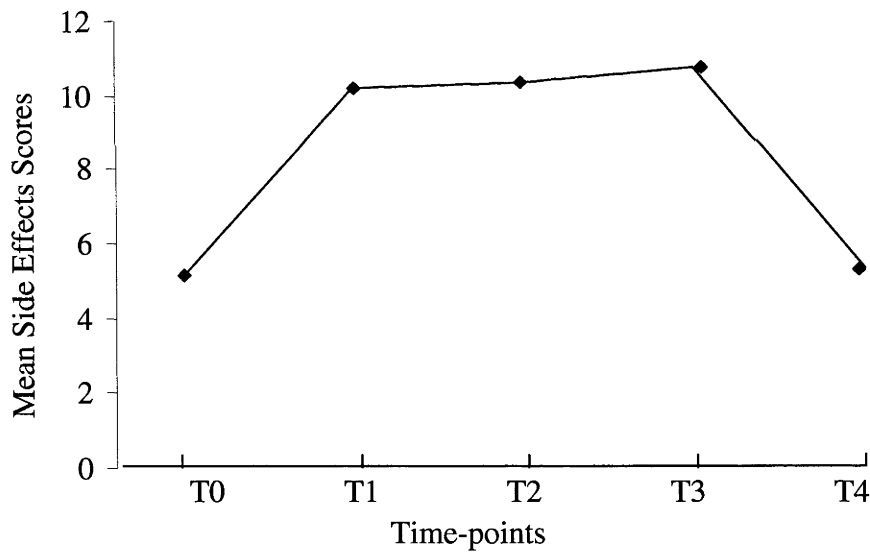


Figure 8. *Mean side effects scores across T0-T4*

9.1.2 Side Effects and Demographic Characteristics

Analyses of differences in side effects according to demographic characteristics were conducted using a Bonferroni adjustment of $\alpha = .008$. A Pearson product-moment correlation showed no association between age and overall side effects ($r = -.22$, $p > .008$). Independent samples t-tests revealed there were significant differences in overall side effects and marital status ($t(51) = -2.90$, $p < .008$), with partnered participants

experiencing significantly greater overall side effects ($M = 6.17$, $SD = 3.88$) than single participants ($M = 3.17$, $SD = 2.85$). There were no significant differences in side effects in terms of education level ($t(51) = 1.15$, $p > .008$), employment status ($t(50) = .51$, $p > .008$), employment intensity ($t(35) = .60$, $p > .008$) and occupation ($t(35) = .60$, $p > .008$).

9.1.3 Side Effects and Health Characteristics

Analyses were conducted to determine the differences in side effects according to health variables using a Bonferroni adjustment of $\alpha = .025$. An independent-samples t-test revealed no significant difference in side effects according to menopausal status ($t(51) = 1.09$, $p > .025$). A one-way ANOVA also revealed no significant difference in side effects according to method of detection ($F(2, 50) = 1.45$, $p > .025$).

9.1.4 Side Effects and Disease Characteristics

Investigation of the differences in side effects according to disease characteristics were conducted using a Bonferroni adjustment of $\alpha = .007$. Pearson product-moment correlations indicated no significant associations between the number of tumours ($r = -.06$, $p > .007$), tumour size ($r = .18$, $p > .007$) and number of axillary nodes involved ($r = -.11$, $p > .007$). Independent samples t-tests showed no significant differences in overall side effects in terms of the presence of DCIS ($t(51) = .94$, $p > .007$) and LCIS ($t(51) = -.87$, $p > .007$). A one-way ANOVA showed no significant difference in side effects according to tumour grade ($F(2, 50) = 1.21$, $p > .007$).

9.1.5 Side Effects and Treatment Characteristics

Investigation of the differences in side effects in terms of treatment characteristics were conducted. Bonferroni adjustments (range of $\alpha = .007$ to $.012$) were applied to the results of analyses at each time-point. At T0, Pearson product-moment correlations revealed no significant association between side effects and the time since diagnosis ($r = -.01$, $p > .012$) and final surgery ($r = -.18$, $p > .012$). An independent samples t-test revealed no significant differences in side effects and number of surgeries ($t(51) = -1.14$, $p > .012$). A one-way ANOVA revealed no significant differences in side effects in terms of the type of surgery ($F(3, 49) = 1.59$, $p > .012$).

At T1, a two-way ANOVA revealed no significant main effect of chemotherapeutic drugs ($F(3, 46) = 2.28, p > .01$) and anti-emetic medication administered ($F(2, 46) = .65, p > .01$) on side effects. No interaction effects were calculated because of the limited number of cases in each cell. Independent-samples t-tests revealed no significant difference in side effects in terms of the treatment reduction ($t(44) = 1.83, p > .01$) and hospitalisation ($t(44) = .72, p > .01$).

At T2, a two-way ANOVA indicated there were no significant main effects of chemotherapeutic drugs ($F(2, 47) = .32, p > .007$) and anti-emetic medication ($F(2, 47) = .34, p > .007$) or an interaction between the two ($F(1, 47) = 2.99, p > .007$) on side effects experienced. Independent-samples t-tests revealed no significant difference in side effects in terms of the use of GCSF support ($t(45) = -1.39, p > .007$), treatment reduction ($t(45) = 1.21, p > .007$), treatment delay ($t(45) = .81, p > .007$) and hospitalisation ($t(45) = -.77, p > .007$).

At T3, a two-way ANOVA indicated there were no main effects of chemotherapeutic drugs ($F(3, 44) = 4.04, p > .008$) and anti-emetic medication ($F(3, 44) = .86, p > .008$) and no interaction effect ($F(4, 44) = 1.28, p > .008$) on side effects experienced. Participants receiving IV CMF as chemotherapeutic drugs and those receiving level 1 anti-emetic medication were excluded from analysis as there was only one case in each group. Independent-samples t-tests revealed no significant difference in side effects in terms of the use of GCSF support ($t(42) = -.95, p > .008$), treatment reduction ($t(42) = -.01, p > .008$) and hospitalisation ($t(42) = -.17, p > .008$). An independent-samples t-test for treatment delay could not be calculated as only two participants were delayed and one of these failed to report side effects experienced.

At T4, independent-samples t-tests revealed that there is no difference in side effects at T4 between those who underwent radiation ($t(34) = -.29, p > .012$) and those that are undergoing endocrine therapy ($t(34) = -.54, p > .012$). Pearson product-moment correlations revealed no significant associations between side effects at T4 and time since chemotherapy ($r = .02, p > .012$) and radiation therapy completion ($r = -.02, p > .012$).

9.1.6 Side Effects and Bone Marrow, Hepatic, and Renal Functioning

To investigate the relationships between bone marrow, hepatic, and renal functioning and side effects reported at T1, T2 and T3, Pearson product-moment correlations were conducted using a Bonferroni adjustment of $\alpha = .006$. The results are presented in Table 42 and reveal there to be no significant associations between bone marrow, renal and hepatic functioning and side effects at T1, T2 and T3. The only exception was a significant, positive and moderate relationship between side effects and the GGT index of hepatic functioning at T1.

Table 42

Intercorrelations Between Bone Marrow, Renal and Hepatic Functioning Indices and Side Effects at T1, T2 and T3 (N=53)

Variable	T1	T2	T3
<i>N</i>	46	47	44
Bone Marrow			
Neutrophils	.12	.04	.09
Renal			
Urea	-.20	-.28	-.19
Creatinine	.03	.07	.01
Hepatic			
Bilirubin	.22	.02	.29
ALT	.31	-.18	.02
AlkP	.06	-.28	-.34
GGT	.60*	-.12	.11
Albumin	-.08	-.19	-.19

* $p < .006$

9.1.7 Side Effects and Anxiety and Depression

Pearson product-moment correlations using a Bonferroni adjustment of $\alpha = .025$ were conducted to investigate the relationships between side effects, anxiety and depression at each time-point. The results are presented in Table 43 and suggest that there are largely significant, moderate to strong, positive associations between anxiety, depression and side effects at T0 to T4.

Table 43

Intercorrelations Between Anxiety, Depression and Side Effects Across T0-T4

Variables	T0	T1	T2	T3	T4
<i>N</i>	53	46	47	44	35
Anxiety-Depression	.47*	.51*	.64*	.65*	.70*
Anxiety-Side Effects	.20	.46*	.65*	.78*	.52*
Depression-Side Effects	.22	.54*	.71*	.70*	.71*

**p* < .025

9.2 Side Effects and Monitoring and Blunting Coping

Lastly, the associations between monitoring, blunting, and the interaction term and side effects were investigated. Pearson product-moment correlations were conducted using a Bonferroni adjustment of $\alpha = .01$. The results are presented in Table 44 and revealed largely positive, small to moderate associations between the variables. These associations were positive, moderate and significant for the interaction term and side effects at T1 and monitoring and side effects at T2.

Table 44

Intercorrelations Between Monitoring, Blunting, the Interaction Term, and Side Effects Across T0-T4

Variables	Side Effects				
	T0	T1	T2	T3	T4
<i>N</i>	53	46	47	44	35
Monitoring	.33	.28	.40*	.31	.33
Blunting	-.02	.24	.18	.13	.38
Monitoring-Blunting	-.04	.48*	.30	.35	.34

**p* < .01

A backward elimination regression analysis was conducted to determine whether the monitoring and blunting coping styles predict the experience of side effects. Side effects was entered as the dependent variable. Monitoring, blunting, the interaction term, intrusive and avoidant ideation, anxiety and depression were entered as predictors. The same demographic, medical, disease and treatment characteristics were included as in the previous regression analyses for anxiety and depression. Chemotherapy treatment

characteristics were also included and consisted of the type of chemotherapeutic drugs administered, anti-emetic medication received, GSCF support received, dose reduction received, treatment delay received, and hospitalisation. The time-line variable and time-point variables for T1, T2, T3 and T4 were entered into the model.

The unstandardised regression coefficients (B), the standard error of the regression coefficient (s.e.), standardised regression coefficients (β), and the T test results are presented in Table 45. The model was significant ($F(13, 212) = 35.29, p < .001$) and accounted for 66% of variance. The interaction term, intrusive and avoidant ideation and depression positively predicted side effects. Participants who used both monitoring and blunting coping and reported experiencing intrusive and avoidant ideation and depression also reported experiencing side effects.

Of the demographic and treatment variables, employment status and having undergone BCS plus TM negatively predicted side effects while the number of surgeries and having undergone BCS positively predicted side effects. Participants who were employed, underwent two surgeries, underwent BCS, and underwent surgeries other than BCS plus TM reported experiencing more side effects compared to those who were retired, underwent one surgery, underwent BCS and underwent surgeries other than BCS plus TM.

Of the treatment variables, receiving Taxol and levels two or three of anti-emetic support positively predicted side effects. Participants who received Taxol and level 2 or 3 of anti-emetic support reported more side effects than those who received chemotherapeutic drugs other than Taxol and level one of anti-emetic support. Of the indices of renal functioning, urea negatively predicted and creatinine positively predicted side effects. Participants with low levels of urea and high levels of creatinine experienced more side effects.

Table 45

Summary of Backward Elimination Regression Analysis for Variables Predicting Side Effects (N=226)

Variables	B	s.e.	β	T
Monitoring-Blunting	.01	.00	.20	4.72**
Intrusive ideation	.10	.05	.16	2.13*
Avoidant ideation	.15	.06	.18	2.57*
Depression	.49	.08	.32	6.35**
Employment status	-1.28	.49	-.11	-2.62**
Number of surgeries	1.82	.65	.15	2.81**
BCS	1.69	.51	.15	3.29**
BCS plus TM	-2.65	.81	-.16	-2.97**
Taxol	2.8	1.03	.12	2.60**
Anti-emetic level 2	2.55	.86	.23	2.95**
Anti-emetic level 3	2.53	.95	.16	2.67**
Urea	-.54	.20	-.25	-2.70**
Creatinine	.05	.02	.32	3.00**

Note. $R^2=.68$, $\Delta R^2=.66$

* $p < .05$, ** $p < .01$

Figure 9 illustrates the model of side effects. The use of blunting indirectly increased side effects via intrusive and avoidant ideation. The use of neither monitoring nor blunting increased side effects both directly and indirectly, via intrusive and avoidant ideation. Like the anxiety model, side effects were increased by intrusive ideation but also avoidant ideation. Depression also increased side effects.

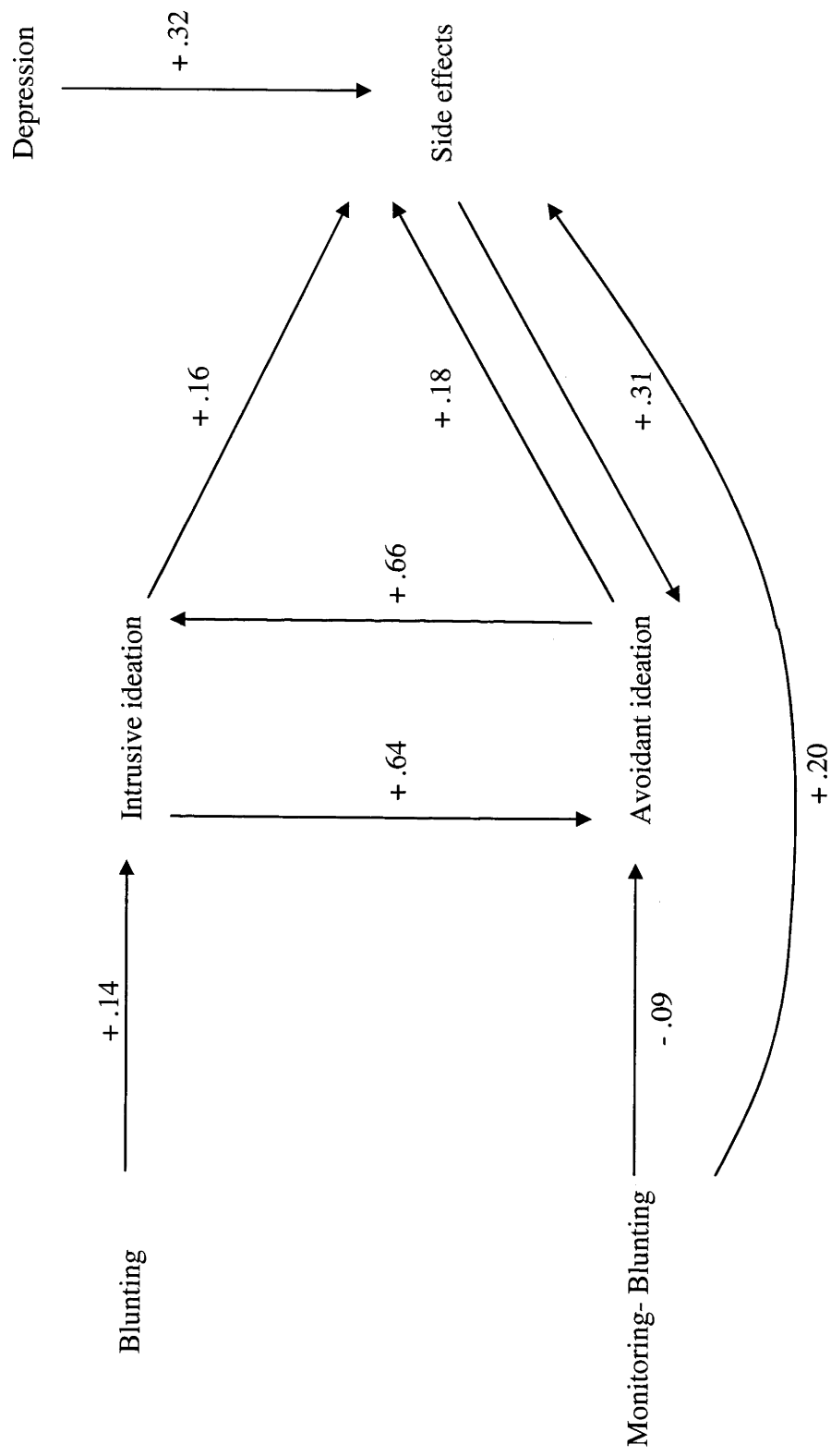


Figure 9. Path model of the influence of monitoring and blunting coping styles on side effects

9.3 Discussion

Participants' experience of side effects before, during and following chemotherapy treatment was investigated. The results revealed that participants reported a broad range of side effects before, during and six months following chemotherapy treatment, although levels of side effects were elevated during chemotherapy. Given that there are no currently utilised measures of side effects experienced in response to adjuvant chemotherapy and the measure utilised in the present study was specifically created, it is not possible to compare the levels of side effects with other samples.

Nonetheless, investigation of the levels of side effects experienced revealed some interesting results. Many participants reported that they were experiencing side effects at baseline. Closer inspection revealed that the side effects experienced were those commonly associated with recovery from breast surgery, including pain, sore muscles, fatigue and difficulty sleeping. Pain and sore muscles were likely due to breast surgery and both of which may contribute to the significant fatigue and difficulty sleeping reported via little or poor sleep. Fatigue may also be due to the effects of a general anaesthetic. Past research has indicated that all of these symptoms are common following breast surgery (NHMRC & NBCC, 2001).

Alternatively, side effects reported after the first, middle and final treatments appeared to be more closely associated with the effects of the chemotherapeutic drugs administered. When considering the pattern of side effects experienced during chemotherapy, there are some differences in the side effects reported after the first and middle chemotherapy treatment compared to the final treatment. Memory problems and sore muscles were more common and nausea was less common after the final treatment compared to the first and middle treatments. This corresponds with changes in the types of chemotherapeutic drugs administered.

A significant number of participants were prescribed AC or EC plus Taxol, with AC or EC received at the first and middle treatments and Taxol at the final treatment. AC and EC often elicit nausea while Taxol elicits muscle soreness (Chap & Haskell, 2001), thus accounting for the increases in sore muscles and decreases in nausea across the treatments. Declines in nausea and vomiting may also be due to the addition of anti-emetic treatments. The failure to reduce nausea and vomiting altogether confers with the past research stating that despite the wide spread use of anti-emetic medication, a

significant number of participants still experience nausea and vomiting (Dibble et al., 2004; Kris et al., 1998; Lee et al., 2005). The fact that the side effects reported before chemotherapy reflected recovery from breast surgery and the side effects after the first treatment reflected those experienced as a result of chemotherapy might explain the lack of association between scores of side effects at baseline and after the first treatment.

As expected, side effects declined on completion of treatment such that the levels of side effects reported at six-month follow-up were equivalent to those reported at baseline. Even so, several of the side effects did not return to baseline levels but instead remained elevated. These side effects included fatigue, memory problems, shortness of breath and coughing. Fatigue is commonly reported in the months following chemotherapy treatment although few explanations are provided for the prolonged experience of fatigue (Beisecker et al., 1997; Bower et al., 2000; de Jong et al., 2002b; Frost et al., 2000; Sadler & Jacobsen, 2001). It is possible that both fatigue and shortness of breath may be explained by a lack of fitness following cancer treatment. The declines in functioning experienced as a result of surgery, chemotherapy, radiation and/or endocrine therapy may have led to decrements in fitness that participants have not yet recovered by follow-up.

Increases in self-reported memory problems in the period following treatment reflect the trends reported in past research but as yet, the nature and reason for such memory problems is unknown (Castellon et al., 2005; Falletti et al., 2005; Jansen et al., 2005; NHMRC & NBCC, 2001; Schagen et al., 1999). The reason for continued elevations in coughing is more difficult to explain. Several participants reported coughing prior to chemotherapy treatment due to regular cigarette smoking. It is possible that the presence of coughing at follow-up is simply the result of those regularly smoking rather than a result of cancer treatment, although it is unlikely that these levels would increase over time. The present study is the first of its kind in assessing chemotherapy side effects following chemotherapy. Clearly further research is needed to confirm the findings and investigate the reasons for elevated levels of certain side effects six-month following chemotherapy compared to baseline.

Similar to the results for anxiety and depression, monitoring and blunting coping styles appeared to play significant roles in the experience of side effects. Again, the coping

styles affected side effects in ways contrary to those expected. As in the models of anxiety and depression, the use of blunting coping increased the levels of intrusive ideation experienced while the use of both monitoring and blunting reduced the levels of avoidant ideation experienced.

Miller's (1996; 1993) theory states that the use of the monitoring coping is associated with increased side effects while blunting coping is associated with reduced side effects. This has been supported in research investigating patients undergoing a several medical procedures and treatments (Miller et al., 1988; Miller & Mangan, 1983; Steptoe & O'Sullivan, 1986), including cancer patients undergoing chemotherapy treatment (Lerman et al., 1990). No research has reported that the use of blunting results in increased levels of side effects.

Intrusive and avoidant ideation each served to increase levels of the other. Consistent with the model of depression, both intrusive and avoidant ideation were then shown to increase levels of side effects. Consistent with both the models of anxiety and depression, side effects were associated with increased avoidant ideation but not intrusive ideation. The ability of intrusive and avoidant ideation to increase side effects has been demonstrated in samples of late stage cancer patients (Manne et al., 2001) and cancer survivors (Lewis et al., 2001). Research has also demonstrated that side effects may increase levels of avoidant ideation (Manne et al., 2001).

In the model of side effects the use of monitoring and blunting was also directly associated with increased side effects. As previously outlined in the discussion of the anxiety and depression models, Krohne (Krohne, 1993) describes people using both monitoring and blunting coping as ineffective copers. He theorises that they are intolerant of both the uncertainty and emotional arousal elicited by stressful situations, intolerances that are relived by monitoring and blunting coping, respectively. They continually switch between coping styles which provides little opportunity for either forms of coping to be effective, resulting in increased side effects. Alternatively, Krohne (Krohne, 1993) states that people who employ neither monitoring nor blunting coping are the most effective copers. They are tolerant of both uncertainty and emotional arousal and are therefore able to strategically employ the use of either

monitoring or blunting as the situation requires. This ensures they effectively deal with the stressful situation and consequently experience fewer side effects.

Similar to the experience of anxiety and depression, side effects appear to be predicted by some demographic, health and treatment characteristics. A relationship was found between marital status and side effects although this relationship was not reported in the regression analyses. Partnered participants reported more side effects than single participants. As discussed, this finding is contrary to the result of past research (de Groot, 2002). Again, it is possible that partnered women's greater spousal and family responsibilities meant that any side effects that might affect physical functioning were noticed. Family's concern about participants' wellbeing prompted frequent questions, which in turn, prompted reflection and awareness of side effects. Secondary gains in the marital relationship may have accounted for increased reporting of side effects (Fishbain et al., 1995).

The only demographic characteristic shown to predict side effects in the regression analysis was employment status. Participants who were employed reported more side effects than those who were retired. It is possible that participants who were employed were more active and therefore noticed any side effects that might affect their physical functioning more than those who were retired and therefore perhaps less active. Many participants who were employed during treatment reported great difficulty physically dealing with work days. As one participant explained, "I pushed myself to work normally."

A number of surgical treatment characteristics significantly predicted side effects, but the nature of the influence of these characteristics appears contradictory. Participants who underwent two surgeries reported more side effects than those who underwent one. Two surgeries involve increased interference to the operated area as well as a second general anaesthetic, all of which may result in significant side effects. On the other hand, participants who underwent BCS reported more side effects than those who underwent other surgeries. Participants who underwent BCS and TM reported fewer side effects. These two findings appear to suggest that few and less invasive surgical treatment is associated with more side effects. The reason for this pattern of results is unknown and requires further investigation.

In terms of the chemotherapy treatment characteristics, the receipt of Taxol and levels 2 and 3 of anti-emetic medication were associated with increased side effects. Taxol does attract significant side effects, although it is unknown why receipt of the other chemotherapeutic drugs did not also result in increased side effects. It is possible that the measure of side effects does not comprehensively capture the full range of side effects experienced in response to adjuvant chemotherapy for breast cancer. The measure might include side effects common to Taxol but uncommon to the other chemotherapeutic drugs. For example, FEC, CMF, AC and EC all have the potential to elicit significant fatigue, nausea, vomiting and loss of appetite whereas Taxol may elicit pain and sore muscles (Chap & Haskell, 2001).

It must be acknowledged that the measure of side effects utilised was by no means a comprehensive measure of the possible side effects experienced. The scale included the most common side effects reported during adjuvant chemotherapy for breast cancer. The scale used may have underestimated the side effects experienced. Participants reported that some side effects encountered were not included in the measure and this has been confirmed by recent literature suggesting several additional side effects that are commonly experienced during chemotherapy. For example, some of these side effects include declines in sexual functioning, peripheral neuropathy and weight gain (Arora et al., 2001; Chap & Haskell, 2001; Young-McCaughn, 1996).

Furthermore, the frequency and functional impairment ratings are combined in the ECOG rating scales. Although the scale is familiar to medical professionals, it may confound information regarding the nature of side effects experienced. Existing measures of negative physical symptoms have typically focused on one dimension of ratings, for example, frequency, functional impairment and distress elicited by symptoms. As a result, the measures have provided different estimations of physical symptoms in the one person (Barresi et al., 2003). One participant felt that the confounding of frequency and impairment meant that, "I often felt that some of the answers I chose were not reflective of my experience." The development of a more comprehensive and accurate measure of side effects is essential for future research. A measure that provides several dimensions of ratings might be more appropriate, although brevity in clinical samples is also critical.

Participants receiving levels 2 and 3 of anti-emetic support reported increased side effects. Anti-emetic support has its own side effects, several of which are included in the measure of side effects. For example, constipation, fatigue, appetite loss and sore muscles are all possible side effects of these levels of support (Grunberg, 2001). Conversely, it may be that those experiencing more side effects overall were more likely to receive anti-emetic medication. This is possible as the side effects assessed are interdependent such that the presence of one might increase the likelihood of another. For example, it would be expected that nausea would result in a loss of appetite, difficulty sleeping and/or fatigue.

In addition to these variables, several indices of hepatic and renal functioning were associated with increased side effects. Participants reporting more side effects also demonstrated higher levels of GGT and creatinine but lower levels of urea. Elevated levels of GGT, creatinine and urea indicate the liver and kidneys are working hard to metabolise the chemotherapeutic drugs. Although urea is increased when the kidneys are taxed, it is efficiently expelled from the body via urine and therefore may account for the negative association with side effects (IDG Books Worldwide, 2000).

In summary, participants reported a wide range of side effects before, during and following chemotherapy treatment for EBC. The pattern of side effects reported indicated that participants experienced more side effects during chemotherapy treatment. Similar to the experience of anxiety and depression, monitoring and blunting coping styles appeared to play significant roles in the experience of side effects but not in the ways expected by Miller's (1996; 1993) theory and past research.

CHAPTER TEN

Monitoring and Blunting Coping Styles and Locus of Control Beliefs

10.1 Locus of Control Beliefs

10.1.1. Locus of Control Beliefs Scores

Next, the relationships between monitoring and blunting coping styles and cancer-specific internal, chance and powerful others locus of control were investigated. Participants' locus of control beliefs were calculated by summary scores of the MHLOC subscales (Wallston et al., 1994). First, the descriptive statistics for internal locus of control (ILOC), chance locus of control (CLOC) and powerful others locus of control (PLOC) across T0 to T4 were investigated. The results are presented in Tables T0 to T4 and are presented in Tables 46, 47 and 48.

Table 46

Descriptive Statistics for Internal Locus of Control Beliefs AcrossT0-T4

Time-point	<i>N</i>	<i>M</i>	<i>SD</i>	Range	Skewness	Kurtosis
T0	53	18.62	5.64	6-30	-.11	.57
T1	46	17.42	6.34	6-30	.01	-.89
T2	47	17.46	6.36	6-32	.08	-.38
T3	44	18.37	6.40	6-29	-.41	-.72
T4	35	19.08	6.23	6-34	-.02	.29

Table 47

Descriptive Statistics for Chance Locus of Control Beliefs AcrossT0-T4

Time-point	<i>N</i>	<i>M</i>	<i>SD</i>	Range	Skewness	Kurtosis
T0	53	17.63	6.85	6-36	.85	.59
T1	46	18.05	6.71	6-36	.50	.19
T2	47	17.79	5.84	6-30	-.09	-.42
T3	44	18.78	6.38	6-35	.33	.15
T4	35	19.33	6.31	6-30	.33	-.46

Table 48

Descriptive Statistics for Powerful Others Locus of Control Beliefs Across T0-T4

Time-point	<i>N</i>	<i>M</i>	<i>SD</i>	Range	Skewness	Kurtosis
T0	53	27.02	4.72	16-36	-.23	-.67
T1	46	26.23	5.35	11-35	-.90	.63
T2	47	26.40	3.79	18-34	-.16	-.39
T3	44	26.36	4.63	16-36	-.44	-.01
T4	35	27.25	4.18	19-36	.34	-.37

Pearson product-moment correlations were calculated to investigate the associations between ILOC, CLOC, and PLOC at adjacent time-points. The results are presented in Tables 49, 50 and 51. There were mostly significant, positive, and moderate to very strong associations between ILOC, CLOC and PLOC scores across T0-T4.

Table 49

Intercorrelations Between Internal Locus of Control Beliefs Across T0-T4

	T0	T1	T2	T3	T4
<i>N</i>	53	46	47	44	35
T0	1	.54*	.58*	.55*	.63*
T1		1	.74*	.75*	.66*
T2			1	.73*	.65*
T3				1	.77*
T4					1

* $p < .05$

Table 50

Intercorrelations Between Chance Locus of Control Beliefs Across T0-T4

	T0	T1	T2	T3	T4
<i>N</i>	53	46	47	44	35
T0	1	.66*	.46*	.37*	.49*
T1		1	.52*	.57*	.49*
T2			1	.79*	.47*
T3				1	.55*
T4					1

**p* < .05

Table 51

Intercorrelations Between Powerful Others Locus of Control Beliefs Across T0-T4

	T0	T1	T2	T3	T4
<i>N</i>	53	47	46	44	35
T0	1	.55*	.50*	.43*	.53*
T1		1	.69*	.71*	.53*
T2			1	.75*	.46*
T3				1	.56*
T4					1

**p* < .05

To investigate the changes in ILOC, CLOC and PLOC across T0 to T4, a series of repeated-measures ANOVAs were conducted. The results revealed that there were significant differences in ILOC scores across T0 to T4 ($F(4, 27) = 2.97, p < .05$, partial eta squared = .09). However, post-hoc paired-samples t-tests revealed no significant differences in ILOC scores at any of the adjacent time-points. Inspection of the means plot presented in Figure 10 indicates that there was a slight decrease in ILOC from T0 ($M = 18.62, SD = 5.64$) to T1 ($M = 17.42, SD = 6.34$) ($t(45) = .99, p > .05$), and increases from T2 ($M = 17.46, SD = 6.36$) to T3 ($M = 18.37, SD = 6.40$) ($t(42) = -1.29, p > .05$). There were no significant differences in CLOC scores ($F(4, 27) = 1.27, p > .05$) and PLOC scores ($F(4, 27) = .59, p > .05$) across T0 to T4. Figures 11 and 12 illustrate mean CLOC and PLOC scores across the time-points.

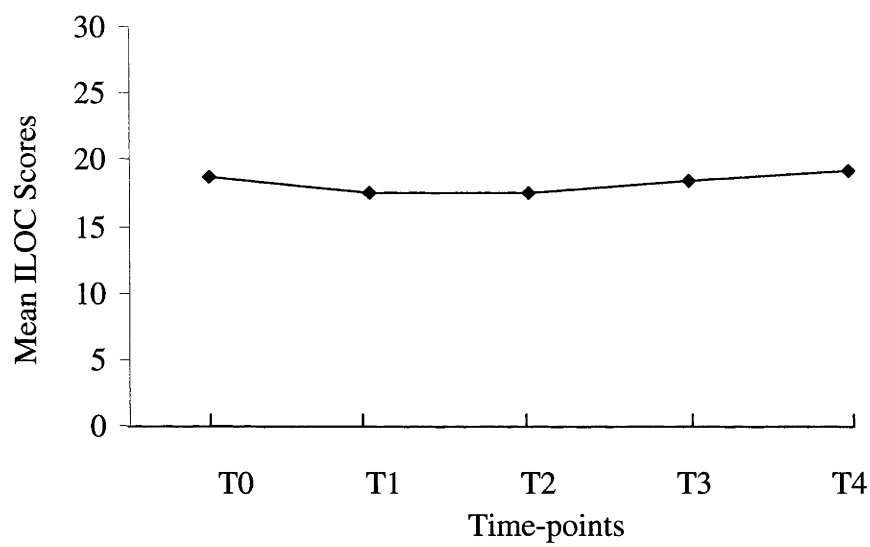


Figure 10. *Mean internal locus of control beliefs scores across T0-T4*

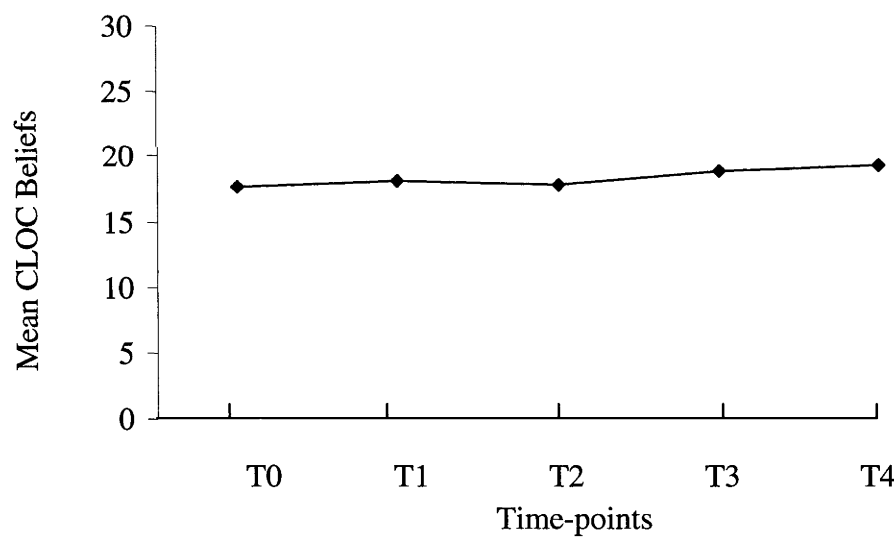


Figure 11. *Mean chance locus of control beliefs scores across T0-T4*

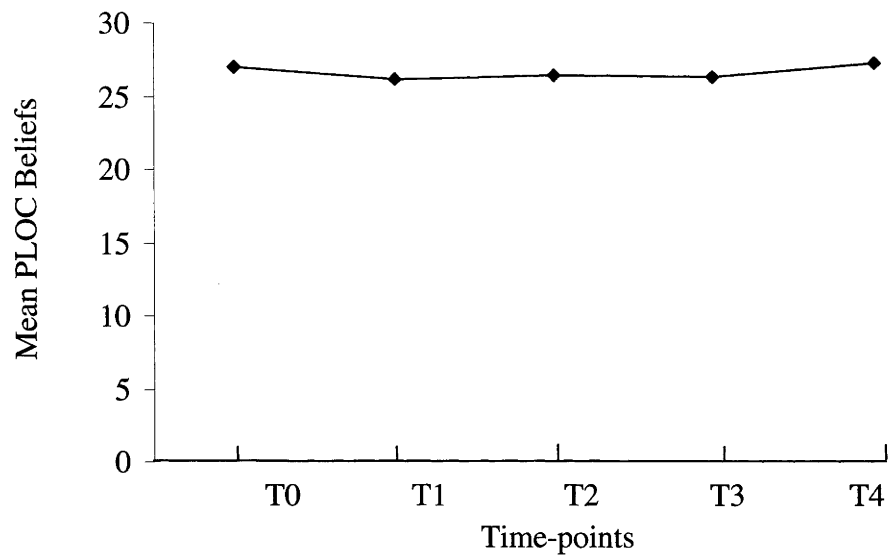


Figure 12. *Mean powerful others locus of control beliefs scores across T0-T4*

Participants appeared to report more PLOC and equivalent ILOC and CLOC across T0 to T4. Paired-samples t-tests were conducted to determine whether the differences were significant, with a Bonferroni adjustment of $\alpha = .017$. The results are presented in Table 52 and reveal that participants reported significantly more PLOC than ILOC and CLOC at all time-points.

Table 52
Paired-samples T-tests Between Internal, Chance, and Powerful Others Locus of Control Beliefs Across T0-T4

Time-points	Variables	N	t	df
T0	PLOC - ILOC	53	52	8.14*
	PLOC - CLOC	53	52	9.28*
T1	PLOC - ILOC	46	45	7.38*
	PLOC - CLOC	46	45	6.73*
T2	PLOC - ILOC	47	46	7.71*
	PLOC - CLOC	47	46	8.81*
T3	PLOC - ILOC	44	43	6.90*
	PLOC - CLOC	44	43	6.90*
T4	PLOC - ILOC	36	35	6.90*
	PLOC - CLOC	36	35	6.61*

* $p < .017$

Pearson product-moment correlations were calculated between the locus of control beliefs across T0 to T4. The results are presented in Table 53. Using a Bonferroni adjustment of $\alpha = .025$, there were small but non-significant associations between ILOC, CLOC and PLOC at all time-points. As expected, ILOC was mainly negatively associated with CLOC and to a lesser extent, PLOC. There were little associations between CLOC and PLOC.

Table 53
Intercorrelations Between Internal, Chance, and Powerful Others Locus of Control Beliefs Across T0-T4

Variables	T0	T1	T2	T3	T4
N	53	46	47	44	35
ILOC - CLOC	-.17	-.32	-.19	-.20	.03
ILOC - PLOC	-.04	.05	-.17	.06	.11
CLOC - PLOC	.22	.08	.08	.15	.11

10.1.2 Locus of Control Beliefs and Demographic Characteristics

A series of analyses were conducted to determine any relationships between locus of control beliefs and demographic variables using a Bonferroni adjustment of $\alpha = .007$. Pearson product-moment correlations revealed no significant association between age and internal ($r = -.21, p > .007$), chance ($r = .03, p > .007$), and powerful others ($r = .02, p > .007$) locus of control beliefs. Independent-samples t-tests were conducted to determine whether there were differences in locus of control beliefs in terms of demographic characteristics. There was a significant difference in education for chance locus of control beliefs ($t(51) = 3.79, p < .007$) with those who were well educated reporting less chance locus of control beliefs ($M = 15.15, SD = 5.27$) compared to those who were less well educated ($M = 21.72, SD = 7.32$). There were no differences in education for internal ($t(51) = -2.32, p > .007$) and powerful others ($t(51) = 1.18, p > .007$) locus of control beliefs.

The results indicated that there were no differences in marital status for internal ($t(51) = -.32, p > .007$), chance ($t(51) = -.38, p > .007$) and powerful others ($t(51) = .90, p > .007$) locus of control beliefs and no differences in state of residence for internal ($t(51) = 1.47, p > .007$), chance ($t(51) = .74, p > .007$), and powerful others ($t(51) = .77, p > .007$) locus of control beliefs. There were no significant differences in employment status for internal ($t(51) = 1.47, p > .007$), chance ($t(51) = -1.03, p > .007$) and powerful others ($t(51) = -1.63, p > .007$) locus of control. There were no significant differences in employment intensity for internal ($t(35) = -.02, p > .007$), chance ($t(35) = -.14, p > .007$) and powerful others ($t(35) = .24, p > .007$) locus of control beliefs. Lastly, the same was true for occupation with no significant differences between occupation and internal ($t(35) = .08, p > .007$), chance ($t(35) = -.43, p > .007$) and powerful others ($t(35) = 1.32, p > .007$) locus of control beliefs.

10.1.3 Locus of Control Beliefs and Health Characteristics

The relationships between health variables and locus of control beliefs were conducted using a Bonferroni adjustment of $\alpha = .012$. Independent-samples t-tests revealed no significant differences in internal ($t(51) = .32, p > .012$), chance ($t(51) = .88, p > .012$) and powerful others ($t(32.61) = .30, p > .012$) locus of control beliefs according to patients' health care status. Levene's test of equality of assumed variance was significant ($F = 5.23, p < .05$) so the t-test with equality of variance not assumed was

considered (Pallant, 2001). Independent-samples t-tests revealed no significant differences in internal ($t(51) = 1.56, p > .012$), chance ($t(51) = -.01, p > .012$) and powerful others ($t(51) = .69, p > .012$) locus of control beliefs according to menopausal status. One-way ANOVAs revealed no difference in internal ($F(3, 49) = 1.47, p > .012$ and $F(2, 50) = .78, p > .012$ respectively), chance ($F(3, 49) = .56, p > .012$ and $F(2, 50) = .38, p > .012$) and powerful others ($F(3, 49) = .58, p > .012$ and $F(2, 50) = .10, p > .012$) locus of control beliefs for the method of detection and referral source.

10.1.4 Locus of Control Beliefs and Disease Characteristics

Analyses were conducted to determine the relationships between locus of control beliefs and disease variables using a Bonferroni adjustment of $\alpha = .008$. Pearson product-moment correlations revealed no significant association between number of tumours and internal ($r = -.01, p > .008$), chance ($r = .01, p > .008$) and powerful others ($r = .17, p > .008$) locus of control beliefs. Pearson product-moment correlations did reveal a significant association between tumour size and internal locus of control beliefs ($r = .36, p < .008$) but not between tumour size and chance ($r = .16, p > .008$) and powerful others ($r = .13, p > .008$) locus of control beliefs. One-way ANOVAs indicated there were no significant differences in tumour grade and internal ($F(2, 50) = 1.01, p > .008$), chance ($F(2, 50) = .32, p > .008$) and powerful others ($F(2, 50) = .26, p > .008$) locus of control beliefs.

Pearson product-moment correlations revealed no significant associations between the number of affected axillary nodes and internal ($r = .21, p > .008$), chance ($r = .04, p > .008$) and powerful others ($r = .20, p > .008$) locus of control beliefs. Independent-samples t-tests revealed no significant differences in the presence of DCIS and LCIS and internal ($t(51) = -.104, p > .008$ and $t(51) = 1.34, p > .008$ respectively), chance ($t(51) = 1.42, p > .008$ and $t(51) = .41, p > .008$) and powerful others ($t(51) = 1.01, p > .008$ and $t(51) = .44, p > .008$) locus of control beliefs.

10.1.5 Locus of Control Beliefs and Treatment Characteristics

The relationships between locus of control beliefs and treatment variables were conducted using a Bonferroni adjustment of $\alpha = .017$. Independent-samples t-tests indicated that there were no significant differences in the number of surgeries and internal ($t(51) = -.40, p > .017$), chance ($t(51) = -.46, p > .017$) and powerful others (t

(51) = 1.14, $p > .017$) locus of control beliefs. One-way ANOVAs showed no differences in surgery type and internal ($F(3, 49) = 1.63, p > .017$), chance ($F(3, 49) = .12, p > .017$) and powerful others ($F(3, 49) = .54, p > .017$) locus of control beliefs. Independent-samples t-tests revealed no difference in the receipt of axillary clearance and internal ($t(51) = 2.00, p > .017$), chance ($t(51) = -1.54, p > .017$) and powerful others ($t(51) = -1.11, p > .017$) locus of control beliefs.

10.1.6 Locus of Control Beliefs and Anxiety, Depression and Side Effects

Pearson product-moment correlations were conducted between locus of control beliefs and anxiety, depression and side effects. A Bonferroni adjustment of $\alpha = .017$ was applied to the results of the analyses. The results are presented in Table 54 and revealed no associations between locus of control beliefs and anxiety, depression and side effects, although there was a small, positive but non-significant association between chance locus of control beliefs and anxiety.

Table 54

Intercorrelations Between Locus of Control Beliefs and Anxiety, Depression and Side Effects (N=53)

Variables	Anxiety	Depression	Side Effects
ILOC	-.06	.09	-.07
CLOC	.32	.17	.14
PLOC	.02	.02	.07

* $p < .017$

10.2. Locus of Control Beliefs and Monitoring and Blunting Coping

Pearson product-moment correlations were calculated between monitoring, blunting and the interaction term and ILOC, CLOC and PLOC at each time point using a Bonferroni adjustment of $\alpha = .01$. The results are presented in Tables 55, 56 and 57, respectively. There were small to moderate, positive but non-significant associations between monitoring, blunting and the interaction term scores and locus of control beliefs at T0 to T4. Exceptions include a moderate, positive and significant association between the interaction term and CLOC at T4 and some small, negative and non-significant associations between blunting and the interaction term, and PLOC.

Table 55

Intercorrelations Between Internal Locus of Control Beliefs and Monitoring, Blunting and the Interaction Term Across T0-T4

Variables	ILOC				
	T0	T1	T2	T3	T4
<i>N</i>	53	46	47	44	35
Monitoring	.32	.21	.11	.21	.10
Blunting	.23	.07	.15	.30	.35
Monitoring-Blunting	.10	-.11	.07	.02	.14

* $p < .01$

Table 56

Intercorrelations Between Chance Locus of Control Beliefs and Monitoring, Blunting and the Interaction Term Across T0-T4

Variables	CLOC				
	T0	T1	T2	T3	T4
<i>N</i>	53	46	47	44	35
Monitoring	.04	.21	.28	.20	.00
Blunting	.14	.22	.22	.22	.18
Monitoring-Blunting	.22	.32	.19	.22	.44*

* $p < .01$

Table 57

Intercorrelations Between Monitoring, Blunting, the Interaction Term and PLOC Across T0-T4

Variables	PLOC				
	T0	T1	T2	T3	T4
<i>N</i>	53	46	47	44	35
Monitoring	.21	.11	.30	.05	-.20
Blunting	.25	-.04	.09	-.05	.10
Monitoring-Blunting	-.03	-.05	-.02	.01	.04

* $p < .01$

Next, backward elimination regression analyses were conducted to determine whether monitoring, blunting and the interaction term significantly predict locus of control beliefs across T0 to T4. For the first analysis, internal locus of control beliefs was entered as the dependent variable. The predictors entered into the model included the remaining locus of beliefs (chance and powerful others locus of control), monitoring, blunting, the interaction term, anxiety, depression, side effects, and demographic, health, disease and treatment characteristics. The time-line variable and the time-point variables for T1, T2, T3 and T4 were entered into the model.

The unstandardised regression coefficients (B), the standard error of the regression coefficient (s.e.), standardised regression coefficients (β), and the T test results of the analysis are presented in Table 58. By design of backward elimination regression analysis, the model was significant ($F(17, 208) = 12.08, p < .001$) and accounted for 56% of the variance in internal locus of control. Chance locus of control and depression negatively predicted internal locus of control while monitoring coping positively predicted internal locus of control. Participants who reported experiencing fewer chance locus of control beliefs, less depression and greater use of monitoring coping reported stronger internal locus of control beliefs.

Of the demographic and health variables, state of residence, marital status and menopausal status negatively predicted internal locus of control. Participants who lived in NSW, were single and pre-menopausal reported more internal locus of control beliefs than those who were living in the ACT, were partnered and post-menopausal. Patient status positively predicted internal locus of control such that participants who had private health care status reported stronger internal locus of control beliefs than those with public health care status. All methods of detecting the disease negatively predicted internal locus of control beliefs which suggest that whichever method of detecting disease participants used, they reported more anxiety than those using other methods.

Of the disease and treatment variables, the number of tumours, LCIS and axillary clearance negatively predicted internal locus of control beliefs. The number of surgeries, undergoing TM and bilateral TM positively predicted internal locus of control beliefs. Participants with fewer tumours, no LCIS, did not undergo axillary clearance,

underwent two surgeries, TM and bilateral TM reported more internal locus of control beliefs.

Table 58

Summary of Backward Elimination Regression Analysis for Variables Predicting Internal Locus of Control Beliefs (N=226)

Variables	B	s.e.	β	T
CLOC	-.12	.05	-.13	-2.28*
Monitoring	.11	.04	.19	3.02**
Depression	-.34	.09	-.19	-3.69**
State of residence	-7.05	.92	-.46	-7.68**
Marital status	-1.70	.77	-.13	-2.20*
Self-exam (accidental)	-10.38	4.61	-.84	-2.25*
Self-exam (BSE)	-10.15	4.67	-.66	-2.17*
Clinical exam	-12.18	4.90	-.46	-2.49*
Routine mammography	-10.79	4.67	-.67	-2.31*
Patient status	3.80	.73	.30	5.22**
Menopausal status	-2.70	.71	-.21	-3.80**
Number of tumours	-.98	.37	-.17	-2.69**
LCIS	-6.86	1.42	-.31	-4.83**
Number of surgeries	2.98	1.01	.22	2.96**
TM	2.79	.81	.23	3.46**
Bilateral TM	5.59	1.78	.20	3.13**
Axillary clearance	-5.66	1.10	-.29	-5.12**

Note. $R^2=.50$, $\Delta R^2=.56$

* $p < .05$, ** $p < .01$

For the next regression analysis, chance locus of control beliefs was entered as the dependent variable. The same variables entered as predictors in the previous analysis were included in this model. The results of the analysis are presented in Table 59. The model was significant ($F(14, 211) = 10.74, p < .001$) and accounted for 38% of variance. The use of monitoring and the use of both monitoring and blunting coping positively predicted chance locus of control beliefs. Participants who used more monitoring coping or both monitoring and blunting coping reported more chance locus

of control beliefs. Anxiety positively predicted and depression and internal locus of control negatively predicted chance locus of control. Participants who reported experiencing more anxiety and less depression and internal locus of control beliefs negatively predicted chance locus of control beliefs.

Education level and patient status positively predicted and employment status negatively predicted chance locus of control. Participants who were less well educated, had public health insurance and were retired reported more chance locus of control than those who were better educated, had private health status and were employed. Tumour size, the numbers of surgeries, undergoing TM and axillary clearance positively predicted and LCIS negatively predicted chance locus of control. Participants with larger tumours, no evidence of LCIS and who underwent two surgeries, TM and axillary clearance reported more chance locus of control than those with smaller tumours, evidence of LCIS and who underwent one surgery, BCS, BCS plus TM and bilateral TM and no axillary clearance.

Table 59
*Summary of Backward Elimination Regression Analysis for Variables Predicting
 Chance Locus of Control Beliefs (N=226)*

Variables	B	s.e.	β	T
Monitoring	.11	.04	.18	2.74**
Monitoring-Blunting	.01	.00	.20	3.53**
ILOC	-.15	.07	-.14	-2.23*
Anxiety	.62	.12	.38	5.25**
Depression	-.29	.13	-.16	-2.30*
Education	-2.03	.83	-.15	-2.45*
Employment status	2.26	.82	.16	2.75*
Patient status	-2.00	.80	-.15	-2.48*
Tumour size	.08	.02	.20	3.37**
Number of surgeries	3.84	.86	.24	3.55**
TM	3.07	.86	.24	3.55**
Axillary clearance	2.63	1.20	.13	2.20*
LCIS	-4.86	1.57	-.21	-3.09**
T0-T4	.63	.24	.14	2.60*

Note. $R^2=.42$, $\Delta R^2=.38$

* $p < .05$, ** $p < .01$

In the final backward elimination regression analysis, powerful others locus of control beliefs were entered as the dependent variable and the same variables entered as predictors. The results of the analysis are presented in Table 60. The model was significant ($F(10, 215) = 7.11, p < .001$) and accounted for 21% of variance. Chance locus of control, the use of monitoring coping and the use of blunting coping positively predicted powerful other locus of control and depression negatively predicted powerful other locus of control. Participants who reported more chance locus of control, used more monitoring or blunting coping, reported less depression and more powerful other locus of control beliefs than those who reported less chance locus of control beliefs, less monitoring or blunting coping and more depression.

Of the demographic variables, age and state of residence positively predicted and education level and occupation negatively predicted powerful other locus of control.

Participants who were older, lived in the ACT, were better educated and were employed in professional work reported more powerful others locus of control. Detection of disease via clinical examination and the number of tumours positively predicted powerful others locus of control beliefs. Participants who detected the disease via clinical examination and had more tumours reported more powerful others locus of control. Chance locus of control beliefs positively predicted powerful others locus of control beliefs such that those participants reporting more chance locus of control beliefs also reported more powerful others locus of control beliefs.

Table 60

Summary of Backward Elimination Regression Analysis for Variables Predicting Powerful Others Locus of Control Beliefs (N=226)

Variables	B	s.e.	β	T
CLOC	.09	.05	.13	2.08*
Monitoring	.07	.03	.16	2.34*
Blunting	.10	.03	.20	3.09**
Depression	-.27	.08	-.21	-3.35**
Age	.13	.03	.26	4.25**
State	1.60	.79	.14	2.03*
Education	-1.61	.62	-.17	-2.59**
Occupation	-2.45	.75	-.20	-3.25**
Clinical exam	2.87	1.25	.15	2.30*
Number of tumours	.97	.26	.22	3.69**

Note. $R^2=.25$, $\Delta R^2=.21$

* $p < .05$, ** $p < .01$

10.3. Discussion

The roles of monitoring and blunting coping styles in locus of control beliefs reported before chemotherapy treatment, after the first, middle and final chemotherapy treatments and six months following chemotherapy were investigated. Overall, participants reported moderate internal and chance locus of control beliefs and strong powerful others locus of control beliefs. Patients diagnosed with breast cancer tend to report stronger powerful others locus of control beliefs compared to internal locus of

control beliefs (Bourjolly, 1999; Bremer et al., 1997; Marks, Richardson, Graham, & Levine, 1986).

The importance of medical professionals, family and friends to participants' experiences of chemotherapy was evident in the comments during and following chemotherapy. Participants overwhelmingly agreed that medical professionals' expertise and support "substantially assisted my recovery" and that "they were people I could turn to who would help willingly" and "they were doing the absolute best they could for me in a thoroughly competent way". Participants also emphasised the importance of family and friends. Many participants felt that they "could not have gotten through it if it weren't for (my husband)" and "friends and family, who all pitched in their support throughout the process".

There appeared to be little change in locus of control beliefs across the time-points. It is thought that health locus of control beliefs change over time with stressful experiences (Wallston et al., 1976; Wallston, 2005b; Wallston et al., 1994) and that the treatment of breast cancer would be one such experience. There were some changes in internal locus of control beliefs, from baseline to after the first treatment cycle and from the middle to final cycles. It is possible that prior to starting chemotherapy, participants were concerned about their ability to cope with the treatment but that with experience, participants became more confident in their ability to cope. Thus, their internal locus of control beliefs increased.

Alternatively, there were no changes in chance and powerful other locus of control beliefs across the time-points. It might be expected that as participants become more accustomed to coping with chemotherapy treatment, they might report less chance locus of control beliefs. However, it is evident that participants required supportive treatment throughout chemotherapy (for example, receiving anti-emetic medication, GCSF support, dose reduction and so on). Perhaps receipt of supportive treatment made participants aware that they were not able to control the effects of chemotherapy and therefore chance locus of control beliefs remained consistent. Indeed, some participants frequently reported frustration at not being able to control their experience of chemotherapy. For example, a common frustration was the inability to avoid the

development of neutropenia, despite doing everything possible to ensure enhanced physical wellbeing.

It might be expected that powerful others locus of control beliefs would also increase across chemotherapy. Chemotherapy treatment often provides opportunities for observing the expertise of medical professionals and receiving support from family and friends, leading to an increase in powerful others locus of control beliefs. Having already received a diagnosis and undergone surgical intervention, participants may have had ample opportunities to receive care and support from medical professionals, family and friends. That is, it is likely that any changes in locus of control beliefs may have already occurred prior to the start of the study. Powerful others locus of control beliefs were already high at baseline so it might be unlikely that these beliefs could increase further. Past research has shown that previous experience with medical professionals significantly determines powerful others locus of control beliefs in patients with renal disease (Christensen, Turner, Smith, Holman, & et al., 1991) and cancer (Andrykowski & Brady, 1994).

Of central importance were the roles of monitoring and blunting in the locus of control beliefs. Participants using the monitoring coping style reported more internal locus of control beliefs. This finding was contrary to expectations. Miller's (Miller, 1996; Miller et al., 1993) theory proposes that in an uncontrollable stressful medical situation, like the diagnosis and treatment of breast cancer, monitoring coping would make participants aware of their limited ability to control the situation. Therefore monitoring would be associated with a less internal locus of control beliefs. Empirical research has reported the same relationship between monitoring and internal locus of control beliefs (Hack & Degner, 1999; Muris et al., 1995b; van Zuuren & Wolfs, 1991).

It is possible that although breast cancer is highly threatening and uncontrollable, it does provide opportunities for participants to perform behaviours that reduce the stressfulness of the situation. Therefore, monitoring behaviour enabled participants to identify these opportunities and feel an increased sense of control and thus more internal locus of control beliefs. In line with the idea, some participants reported that receiving information on their diagnosis and treatment "made it easier to know what to expect" and therefore do things to prepare for the treatment. For example, organising time off

work, making child care arrangements and completing effortful household chores before treatment.

As expected, participants using a monitoring coping style reported more chance locus of control belief. This supports Miller's (Miller, 1996; Miller et al., 1993) theory that monitoring is associated with more chance locus of control beliefs in an uncontrollable stressful situation because monitoring serves to make participants acutely aware of the limits of their ability to control the situation. This relationship has not been demonstrated in the empirical research. Participants using both a monitoring and blunting coping style also reported more chance locus of control. It is thought that people using both monitoring and blunting coping are thought to alternate between both forms of coping without allowing sufficient time to determine if the coping is successful (Krohne, 1993). As a result, participants employing this coping style might feel that there is little that they can do to affect the situation and therefore their beliefs in chance locus of control are strengthened. Again, no research has demonstrated this relationship.

Participants using a monitoring coping style also reported more powerful others locus of control beliefs. This supports Miller's (Miller, 1996; Miller et al., 1993) theory that monitors believe that medical professionals are able to control their medical conditions. As stated, information seeking about a stressful situation may make monitors aware of the limits of their control as well as identifying other people who are able to exert control over the situation. In the medical setting, this would be medical professionals. It has even been suggested that one purpose of monitoring behaviour is to develop relationships with these people. Past research has supported the association between monitoring and powerful others locus of control beliefs (Miller et al., 1988).

Participants using a blunting coping style also reported more powerful others locus of control beliefs. This finding is in contrast to Miller's (Miller, 1996; Miller et al., 1993) theory that blunting is associated with more internal locus of control beliefs. Perhaps participants who blunt or avoid information are not aware of actions they can perform to control the situation and instead hold beliefs that others are able to do something to control the situation. It is also possible that participants with a blunting coping style are aware of actions they can perform to reduce the stressfulness of the situation but have less information about how to implement these actions and are therefore less confident

about performing them. As a result, they prefer to rely on others to do something about stressful situations. No research has demonstrated a link between blunting and locus of control beliefs.

Although the monitoring and blunting coping styles were consistent predictors of locus of control beliefs, there were several other demographic, health, disease and clinical characteristics that were consistent predictors of locus of control beliefs. Indeed, investigation of the beta weights shows these characteristics accounted for similar amounts of variance in locus of control beliefs as the coping styles. The most consistent of these was depression. Participants experiencing more depression reported less internal, chance and powerful other locus of control beliefs.

People who are experiencing significant depressive symptoms often report feelings of helplessness and hopelessness (American Psychiatric Association, 1994). It might be reasoned that participants feeling hopeless and/or helpless are less likely to believe that all situations, including stressful situations, are controllable by either internal or external factors. People experiencing depressive symptoms also often report a lack confidence in their own abilities, and this might extend to stressful situations (American Psychiatric Association, 1994). They might therefore hold fewer internal, chance and powerful others locus of control beliefs. Previous research has demonstrated participants experiencing high levels of distress also report fewer locus of control beliefs (Cull et al., 2001).

The consistent demographic characteristics predicting locus of control beliefs included the state of residence and education level. Participants living in NSW reported more internal and less powerful others locus of control beliefs compared to those living in the ACT. When encountering concerns or problems with chemotherapy treatment and its side effects, participants living in the ACT were more able to access medical professionals and services than those in NSW, who had to rely more on their personal resources. This might have the effect of enhancing powerful others locus of control beliefs in ACT residents while enhancing internal locus of control beliefs in NSW residents.

Participants who were better educated reported less chance and powerful others locus of control beliefs compared to those who were less well educated. This is in line with past research that shows that people with higher levels of education report more internal and less chance and powerful others locus of control beliefs. People who are better educated may be more aware of ways in which they can affect their health care. This association has been found in women at risk of and diagnosed with breast cancer (Barroso et al., 2000; Helmes et al., 2002), although it has not been consistent (Tittle, Chiarelli, McGough, McGee, & McMillan, 2002).

Participants with private health care status reported more internal and less chance locus of control beliefs. This is not surprising as those people who believe they are able to control their health would be more likely to engage in disease prevention activities of which acquiring private health cover might be considered one such activity. Past research has shown that people with greater internal locus of control beliefs engage in a range of health prevention activities. For example, women with internal locus of control beliefs are more likely to engage in breast cancer screening or those with breast cancer are more likely to take nutritional supplements than those with external locus of control beliefs (Aro et al., 1999; Borrayo & Guarnaccia, 2000; Bundeck et al., 1993; Fajardo et al., 1992; Franco et al., 2000; Glenn & Moore, 1990; Murray & McMillan, 1993; Patterson et al., 2003).

A range of disease and surgical treatment characteristics predicted locus of control beliefs. However, none of these characteristics were consistent predictors of beliefs as different disease and treatment characteristics predicted different beliefs. When the characteristics are considered as a whole, it appears that participants with less extensive disease reported more internal locus of control beliefs while participants with more extensive surgical treatment reported more internal and chance locus of control beliefs. Participants with less extensive disease but more extensive treatment might feel less vulnerable to the disease and perhaps more in control of outcomes and therefore enhanced internal locus of control beliefs. As previously stated, research has confirmed that patients with more acute and chronic illnesses reported more chance and less internal locus of control beliefs (Andrykowski & Brady, 1994; Christensen et al., 1991). Alternatively, participants undergoing more extensive surgery may have had less choice in the type of surgery required and therefore reported enhance chance locus of control

beliefs. It is also possible that participants with more chance locus of control beliefs felt compelled to do everything within their control to affect outcomes and therefore opted for more extensive surgery.

In summary, participants' locus of control beliefs were remarkably consistent before, during and following chemotherapy treatment. Participants reported significantly more powerful others locus of control beliefs compared to internal and chance locus of control beliefs. Monitoring and blunting coping styles played a significant role in participants' locus of control beliefs. The roles of monitoring and blunting coping were not entirely consistent with Miller's (Miller, 1996; Miller et al., 1993) theory, although it should be noted that little past research has been conducted and confirmed the theorised relationships.

CHAPTER ELEVEN

Monitoring and Blunting Coping Styles and Risk Perception

11.1 Risk Perception

11.1.1 Comparative Risk Perception Calculation

To investigate whether monitoring, blunting and the interaction term were associated with levels of perceived risk of developing breast cancer, a series of analyses were conducted. First, while participants reported their levels of personal risk perception (Personal RP) and peer risk perception (Peer RP), a third score was calculated to estimate the extent to which personal risk perception differed from peer risk perception. This score was referred to as comparative risk perception (Comparative RP) and was calculated using the following formula; $X_{prp} - X_{pro} = X_{prc}$, where X_{prp} is the personal risk perception score and X_{pro} is the peer risk perception score.

11.1.2 Risk Perception Estimates

Descriptive statistics were conducted and are presented in Table 61. The results indicate that participants reported a broad range of personal, peer and comparative perceived risks. It appeared that participants reported similar estimates of personal and peer risk perception. This was confirmed by a significant, positive and strong Pearson product-moment correlation between personal and peer risk perception ($r = .87, p < .05$) and a non-significant paired-samples t-test indicated that participants reported similar levels of personal and peer risk perception ($t(35) = -1.36, p > .05$).

Table 61
Descriptive Statistics of Personal, Peer and Comparative Risk Perception (N=35)

Variables	<i>M</i>	<i>SD</i>	Range	Skewness	Kurtosis
Personal RP	4.56	2.20	1.0 - 9.0	.40	-.37
Peer RP	4.81	1.93	2.0 - 9.0	.49	-.03
Comparative RP	-.25	1.10	-4.0 - 2.5	-1.13	4.89

Frequencies were calculated to determine the percentages of participants who estimated their risk to be equivalent, greater or lesser than others. The results are presented in

Table 62 and indicate that the majority of participants reported their personal risk to be equivalent to their peers.

Table 62
Frequencies (%) of Participants Reporting Equivalent, Greater or Lesser Comparative Perceived Risks (N=35)

Comparative RP	<i>f (%)</i>	<i>(n)</i>
Lesser	20.0	(7)
Equivalent	74.3	(26)
Greater	5.7	(2)

11.1.3 Risk Perception and Demographic Characteristics

Analyses were conducted to assess any differences in risk perception according to demographic variables. A Bonferroni adjustment of $\alpha = .008$ was applied to the results of the analyses of demographic characteristics. Pearson product-moment correlations revealed no significant associations between age and personal ($r = .06, p > .008$), peer ($r = -.06, p > .008$) and comparative ($r = -.02, p > .008$) risk perception. Independent-samples t-tests showed no significant differences in personal ($t(34) = -1.26, p > .008$), peer ($t(34) = -1.92, p > .008$) and comparative ($t(34) = .74, p > .008$) risk perception for marital status and no significant differences in personal ($t(34) = 1.08, p > .008$), peer ($t(7.03) = 1.02, p > .008$) and comparative ($t(34) = -.28, p > .008$) risk perception for state of residence. Levene's test of equality of variance was significant ($F = 5.53, p < .05$) for the test of marital status and peer risk perception so the t-test with equality of variance not assumed was considered (Pallant, 2001).

There were no significant differences in personal ($t(34) = .75, p > .008$), peer ($t(34) = .54, p > .008$) and comparative ($t(34) = .55, p > .008$) risk perception by education level. There were no significant differences in personal ($t(34) = .26, p > .008$), peer ($t(34) = .01, p > .008$) and comparative ($t(34) = .50, p > .008$) risk perception by employment status and in personal ($t(24) = .66, p > .008$), peer ($t(24) = .83, p > .008$) and comparative ($t(24) = -.14, p > .008$) risk perception by employment intensity. Lastly, there were no significant differences in personal ($t(24) = .27, p > .008$), peer ($t(9.07) = -.27, p > .008$) and comparative ($t(24) = 1.21, p > .008$) risk perception by occupation. Levene's test of equality of variance was significant ($F = 5.55, p < .05$) for

the test of occupation and peer risk perception so the t-test with equality of variance not assumed was considered (Pallant, 2001).

11.1.4 Risk Perception and Health Characteristics

Analyses of the differences in risk perception according to health variables were conducted using a Bonferroni adjustment of $\alpha = .012$. Independent-samples t-tests show that there were no differences in personal ($t(34) = -.48, p > .012$), peer ($t(34) = .19, p > .012$) and comparative ($t(34) = -1.32, p > .012$) risk perception by patient health care status and in personal ($t(34) = 1.05, p > .012$), peer ($t(34) = 1.06, p > .012$) and comparative ($t(34) = .24, p > .012$) risk perception by menopausal status. One-way ANOVAs revealed no significant differences in personal ($F(3, 32) = 1.96, p > .012$ and $F(2, 33) = .81, p > .012$ respectively), peer ($F(3, 32) = 1.79, p > .012$ and $F(2, 33) = .72, p > .012$) and comparative ($F(3, 32) = 2.30, p > .012$ and $F(2, 33) = .35, p > .012$) risk perception in terms of the method of detection and referral source.

11.1.5 Risk Perception and Disease Characteristics

Analyses were also conducted to determine differences in risk perception and disease characteristics using a Bonferroni adjustment of $\alpha = .008$. Pearson product-moment correlations revealed no significant associations between the number of tumours and personal ($r = .30, p > .008$), peer ($r = .18, p > .008$) and comparative ($r = .28, p > .008$) risk perception, tumour size and personal ($r = -.14, p > .008$), peer ($r = .05, p > .008$) and comparative ($r = -.37, p > .008$) risk perception and number of affected axillary nodes and personal ($r = .20, p > .008$), peer ($r = .24, p > .008$) and comparative risk perception ($r = -.01, p > .008$).

One-way ANOVAs showed no difference in tumour grade and personal ($F(2, 33) = .27, p > .008$), peer ($F(2, 33) = .44, p > .008$) and comparative risk perception ($F(2, 33) = .18, p > .008$). Independent-samples t-tests revealed no significant differences in personal ($t(34) = .01, p > .008$ and $t(34) = -3.25, p < .008$ respectively), peer ($t(34) = -.09, p > .008$ and $t(34) = 1.79, p > .008$) and comparative risk perception ($t(34) = .18, p > .008$ and $t(34) = -.33, p > .008$) in terms of the presence of DCIS and LCIS.

11.1.6 Risk Perception and Treatment Characteristics

Analyses were conducted to determine differences in risk perception according to the receipt of radiation and endocrine therapy. A Bonferroni adjustment of $\alpha = .012$ was applied to the results of the analyses. Independent-samples t-tests revealed no differences in personal ($t(34) = -1.19, p > .012$ and $t(34) = -1.72, p > .012$ respectively), peer ($t(34) = -.77, p > .012$ and $t(34) = -1.59, p > .012$) and comparative risk perception ($t(34) = -1.02, p > .012$ and $t(34) = -.62, p > .012$) and the receipt of radiation therapy and endocrine therapy, respectively. Pearson product-moment correlations showed no significant association between receipt of radiation and endocrine therapy and personal ($r = .19, p < .012$ and $r = .08, p < .012$), peer ($r = .21, p < .012$ and $r = -.05, p < .012$) and comparative risk perception ($r = .00, p < .012$ and $r = .25, p < .012$).

11.1.7 Risk Perception and Anxiety, Depression and Side Effects

Pearson product-moment correlations using a Bonferroni adjustment of $\alpha = .017$ were conducted to determine whether there were associations between risk perception and anxiety, depression and side effects at T4. As shown in Table 63, there are some mainly negative, small but non-significant associations between risk perception and anxiety, depression and side effects.

Table 63

Intercorrelations of Personal, Peer, and Comparative Risk Perception and Anxiety, Depression and Side Effects at T4 (N=35)

Variables	Personal RP	Peer RP	Comparative RP
Anxiety	-.15	-.13	-.06
Depression	-.04	-.09	.06
Side Effects	-.23	-.10	-.23

11.2 Risk Perception and Monitoring and Blunting

A series of Pearson product-moment correlations using a Bonferroni adjustment of $\alpha = .017$ were conducted to determine the associations between risk perception and monitoring, blunting and the interaction term. As shown in Table 64, there appear to be positive, small and non-significant associations between monitoring and personal risk

perception and negative, small and non-significant associations between blunting and the interaction term and peer and comparative risk perception.

Table 64
Intercorrelations of Personal, Peer and Comparative Risk Perception and Monitoring, Blunting, and the Interaction Term (N=35)

Variables	Personal RP	Peer RP	Comparative RP
Monitoring	.29	.29	.07
Blunting	-.31	-.18	-.30
Monitoring-Blunting	-.22	-.12	-.23

To investigate these findings further, a series of hierarchical multiple regression analyses were conducted to determine the extent to which monitoring, blunting, and the interaction term predicted personal, peer, and comparative risk perception. Given the modest sample available for the regression analyses, a selection of background variables was included. These variables consisted of education level, number of tumours, type of surgery and receipt of endocrine therapy. Education level was chosen as past research suggests it may be linked with risk perceptions (Culver et al., 2001; Lerman et al., 1996). The number of tumours was selected as an indicator of the extensiveness of the disease while the type of surgery received was an indicator of the extensiveness of surgical intervention, both of which might affect participants’ feelings of vulnerability to the disease and therefore risk perception estimates. The receipt of endocrine therapy indicates whether participants were receiving active treatment at the time of estimating perceived risks.

To determine the amount of variance in personal risk perception accounted for by monitoring, blunting and their interaction, risk perception was entered into the hierarchical regression equation as the dependent variable. Peer risk perception was entered in the first step, education level, number of tumours, type of surgery and receipt of endocrine therapy were entered in the second step, monitoring and blunting were entered in the third step, and the interaction term was entered in the fourth step. Investigations of the assumptions of regression analyses were conducted. With the use of a $p < .001$ criterion for Mahalanobis distance, no outliers were identified.

The unstandardised regression coefficients (B), the standard error of the regression coefficient (s.e.), standardised regression coefficients (β), and the T test results are presented in Table 65. The overall model with all variables included was significant ($F(8, 27) = 21.05, p < .05$) and accounted for 82% of variance in personal risk perception. Peer risk perception, the use of blunting coping and the number of tumours all made significant unique contributions to personal risk perception. Participants who reported more peer risk perception and had more tumours reported greater personal risk perception. Participants who reported the use of blunting reported lower personal risk perception.

Table 65
Summary of Hierarchical Multiple Regression Analysis for Variables Predicting Personal Risk Perception (N=35)

Variables		B	s.e.	β	T
Step 1	Peer RP	.77	.10	.68	7.73**
Step 2	Number of tumours	.41	.15	.22	2.76**
	Education	-.28	.17	-.13	-1.65
	Surgery type	-.32	.31	-.09	-1.04
	Endocrine therapy	.73	.37	.16	1.96
Step 3	Monitoring	.03	.02	.12	1.44
	Blunting	-.05	.02	-.23	-2.74*
Step 4	Monitoring-Blunting	-.00	.00	-.17	-1.96

Note. Step 1 $R^2=.75, \Delta R^2=.74$, Step 2 $R^2=.80, \Delta R^2=.77$, Step 3 $R^2=.84, \Delta R^2=.80$, Step 4 $R^2=.86, \Delta R^2=.82$

* $p < .05$, ** $p < .01$

To investigate this finding further, scatterplots of blunting on personal risk perception were generated. The results indicate a negative association between blunting and personal risk perception and are presented in Figure 13.

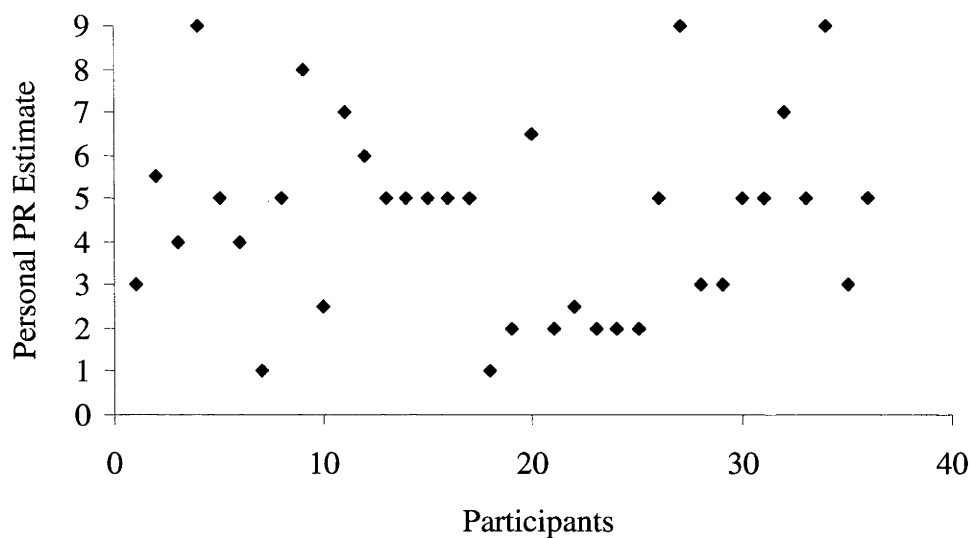


Figure 13. Distribution of Personal Perceived Risks by Blunting Scores

Participants’ blunting scores were divided into tertiles such that group 1 reported the lowest scores on blunting, group 2 the middle scores and group 3 the highest scores. A one-way ANOVA was conducted to determine whether there were significant differences in personal risk perception for the blunting tertile groups. The results of indicated no significant differences in personal risk perception for the blunting groups ($F(2, 33) = 1.28, p > .05, \eta^2 = .07$). Inspection of the means indicate that group1 scores lower ($M=3.86, SD=2.24$) than group 2 ($M=4.42, SD=2.28$), which in turn scored lower than group 3 ($M=5.54, SD=1.85$) on personal risk perception. That is, high blunting scores were associated with lower personal risk perception. A means plot is presented in Figure 14.

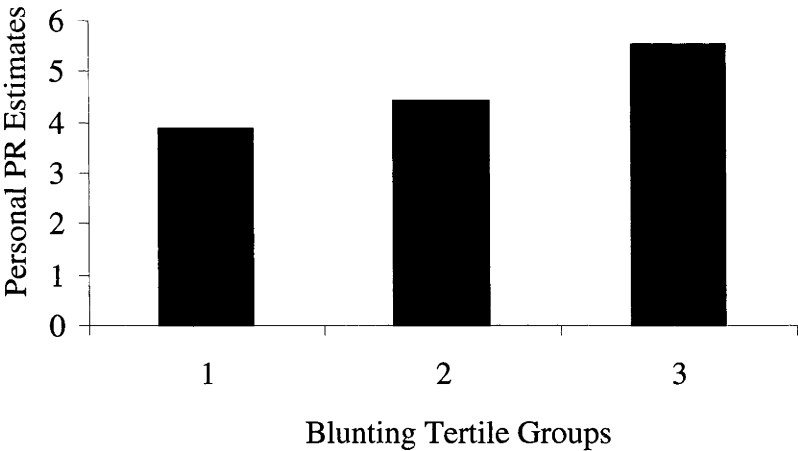


Figure 14. Mean Personal Perceived Risk of Blunting Tertile Groups

The same process was repeated for peer risk perception. Peer risk perception was entered as the dependent variable. Personal risk perception was entered in the first step, education level, number of tumours, type of surgery and receipt of endocrine therapy were entered in the second step, monitoring and blunting coping were entered in the third step and the interaction term was entered in the fourth step. The results of the regression analysis of peer risk perception are presented in Table 66. With the use of a $p < .001$ criterion for Mahalanobis distance, no outliers were identified.

The overall model was not significant ($F(8, 27) = 12.83, p < .05$). Only personal risk perception made a significant unique contribution to peer perceived risk. Participants who reported higher peer risk perception estimates also reported higher personal risk perception. Monitoring, blunting and the interaction term did not make a significant contribution.

Table 66
Summary of Hierarchical Multiple Regression Analysis for Variables Predicting Peer Risk Perception (N=35)

Variables		B	s.e.	β	T
Step 1	Personal RP	.90	.12	1.02	7.73**
Step 2	Number of tumours	.12	.19	.06	.61
	Education	-.30	.17	-.18	-1.74
	Surgery type	.41	.33	.13	1.26
	Endocrine therapy	-.32	.42	-.08	-.76
Step 3	Monitoring	-.00	.02	-.01	-.09
	Blunting	.03	.02	.13	1.13
Step 4	Monitoring-Blunting	.00	.00	.10	.92

Note. Step 1 $R^2=.75$, $\Delta R^2=.74$, Step 2 $R^2=.77$, $\Delta R^2=.73$, Step 3 $R^2=.78$, $\Delta R^2=.73$, Step 4 $R^2=.79$, $\Delta R^2=.73$

* $p < .05$, ** $p < .01$

For the analysis of comparative risk perception, comparative risk perception was entered as the dependent variable. Background variables were entered in the first step, monitoring and blunting coping were entered in the second step and the interaction term was entered in the third step. With the use of a $p < .001$ criterion for Mahalanobis distance, no outliers were identified.

The results of the analysis are presented in Table 67 and reveals that the overall model was not significant ($F(7, 28) = 2.03, p > .05$). Only the number of tumours made a significant unique contribution to comparative risk perception. Monitoring, blunting and the interaction term did not make significant unique contributions to comparative risk perception.

Table 67

Summary of Hierarchical Multiple Regression Analysis for Variables Predicting Comparative Risk Perception (N=35)

Variables		B	s.e.	β	T
Step 1	Number of tumours	.36	.16	.39	2.28*
	Education	-.18	.18	-.17	-1.02
	Surgery type	.48	.38	.21	1.26
	Endocrine therapy	-.41	.33	-.22	-1.26
Step 3	Monitoring	.01	.02	.10	.56
	Blunting	-.04	.02	-.32	-1.90
Step 4	Monitoring-Blunting	-.00	.00	-.24	-1.36

Note. Step 1 $R^2=.18$, $\Delta R^2=.08$, Step 2 $R^2=.29$, $\Delta R^2=.15$, Step 3 $R^2=.34$, $\Delta R^2=.17$

* $p < .05$, ** $p < .01$

11.3. Discussion

Perceived risks of recurrence six months following completion of chemotherapy treatment were investigated. At this point, all participants have completed active treatment with the exception of the 63% of participants receiving endocrine therapy. Inspection of the risk perception estimates revealed that participants reported a wide range of personal and peer risk perception. The mean personal and peer risk perception estimates were similar, indicating that participants perceived their own level of risk as being comparable to peers' level of risk. Indeed, three-quarters of participants reported that personal and peer risks were the equivalent, one-fifth reported that their risk was lower and the remaining few participants felt their risk was higher than peers. That is, participants were slightly optimistic about their risk of recurrence compared to their peers.

It is difficult to compare the levels of personal perceived risk to other samples. Little empirical research of perceived risk of recurrence has been conducted and instead, research has focused on the perceived risk of developing cancer for the first time. This research has also tended to utilise diverse measures of risk perception, typically designed specifically for the study (Absetz et al., 2000; Bottorff et al., 2004; Bowen et al., 2003; Culver et al., 2001; Cunningham et al., 1998; Diefenbach, Schnoll, Miller, & Brower, 2000; Gil et al., 2003; Kent et al., 2000; Lipkus et al., 2005; Weinstein et al.,

2004). Given the growing interest in risk perceptions regarding future cancer recurrence, it would be prudent for future research to investigate the construct further and determine the best way in which to assess risk perceptions. This would enable an accurate estimation of perceived risks reported and comparisons to be made across samples.

The relationship between the monitoring and blunting coping styles and perceived risk estimates indicate that the coping styles play a limited yet significant role in participants' personal perceived risks. Participants who prefer the blunting coping style reported lower personal risk perception. This finding confirms Miller's (1996; 1993) theory that blunting is associated with reduced perceived risk of developing a serious medical condition but does not support the theory that monitoring coping is associated with increased risk perception. Of the few studies conducted regarding coping styles and risk perception, the results have supported the association between monitoring and increased risk perception (Schwartz et al., 1995; Zakowski et al., 1997).

According to Miller (1996; 1993), the blunting coping style results in lowered estimates for two reasons. First, participants using blunting coping avoid all information about the stressful situation, including the risks incurred. Second, blunting coping is also thought to elicit lower levels of psychological distress which in turn, might make patients feel less vulnerable in stressful situations. Thus, blunting results in low levels of risk perception. However, the second assertion appears to be implausible in the current study. The results reported previously state that participants using blunting coping report greater levels of distress than those not using blunting coping.

The strongest predictor of personal risk perception was peer risk perception while the strongest predictor of peer risk perception was personal risk perception. This finding is not surprising given the strong association between the two risk estimates. The background variables played little role in participants' risk estimates. Only the number of tumours was significantly associated with personal risk perception. It is understandable that participants with more extensive disease would feel more vulnerable to developing breast cancer again in the future. The number of tumours is just one possible indicator of the extent of disease. Future research is needed to investigate other disease characteristics and their effect on perceived risks.

In summary, participants reported a broad range of risk perception estimates. Monitoring and blunting appeared to have a significant yet limited influence on the experience of perceived risk of recurrence. However, it should be noted that the regression analyses conducted involved a small sample of participants in comparison to the number of predictor variables entered in the analyses. Indeed, the assumption that at least 8 cases are required per predictor variable was violated in the analyses (Tabachnik & Fidell, 2001). Consequently, the results and conclusions drawn from the analyses should be considered tentative. Further research is required due to the small number of participants who completed the six-month follow-up questionnaire and the cross-sectional nature of the investigation of risk perception.

CHAPTER TWELVE

Conclusions

The present study signifies one of the first and most comprehensive attempts to examine women's experience of adjuvant chemotherapy for EBC. Women's physical and psychological wellbeing before, during and six months following treatment was intensively examined. The results highlighted the importance of understanding the role of coping styles in the experience of chemotherapy and as such, offer numerous and significant theoretical and clinical implications.

In terms of the theoretical implications, the study has significantly extended the existing knowledge of coping and its role in the experience of stressful medical situations. The study is one of few to investigate the theoretical conceptualisation and empirical measurement of monitoring and blunting coping styles. The results suggest that the coping styles are likely to be mutually exclusive coping constructs but raised doubts regarding the stability of monitoring and blunting coping. It is thought that monitoring and blunting are fairly independent of situational and personal factors (Krohne, 1993; Miller, 1996; Miller et al., 1993) however participants reported use of the coping styles changed after the experience of chemotherapy. It appears then that the coping styles are more vulnerable to change in the face of significant experiences than previously thought. The results also demonstrated the adequate reliability of the coping measures but highlighted concerns about their construct validity. It appears that blunting coping is a more heterogeneous construct than that represented in existing measures. The results indicate that a more accurate conceptualisation and measurement of the coping styles is a priority for future research.

The present study considered both monitoring and blunting coping styles as continuous variables. This ensured that an accurate understanding of the roles of monitoring, blunting and their interaction in physical and psychological wellbeing was achieved. Past research has tended to consider either the role of monitoring only (Miller et al., 1996a; Schwartz et al., 1995; Tercyak et al., 2001) or has divided people into groups of particular coping styles according to median split procedure or cluster analysis (Hack & Degner, 1999; McKinnon, 2001; Shapiro et al., 1997; Voss et al., 2006). Past research

has focused on monitoring as initial research revealed no influence of blunting on outcomes. However, the scales utilised in much of the research have since been shown to be poor measures of blunting. The decision to disregard the role of blunting coping in physical and psychological wellbeing may have been premature. The tendency to combine the scores on coping scales into groups also results in a loss of information regarding the full range of variation in monitoring and blunting use and reduces sample sizes on which analyses are conducted.

It is therefore likely that the results of past research are misleading due to the limited and/or inappropriate examination of coping styles. Indeed, the results of the present study demonstrate that the use of blunting coping and both monitoring and blunting coping may have significant roles to play in physical and psychological wellbeing. It is crucial that future research considers the use of monitoring, blunting and the interaction between the two coping styles in order to better understand the nature of the coping styles and their effects on wellbeing. The present study investigated the interaction between the coping styles via the creation of an interaction term. It is possible that this may be a simple and effective method of investigating the interaction between monitoring and blunting coping styles in future research.

The study extended the research on coping styles to consider a clinical sample undergoing a highly stressful and prolonged medical treatment. Past research has focused on non-clinical samples of mainly undergraduate students (Miller, 1987; Muris & de Jong, 1993; Muris & Schouten, 1994; Muris & Van Zuuren, 1992; Muris et al., 1994c; Muris et al., 1994d; Muris et al., 1994e; van Zuuren & Muris, 1993; van Zuuren & Wolfs, 1991), and small clinical samples (Miller et al., 1988; Miller & Mangan, 1983; Miller et al., 1994; Muris et al., 1993a; Muris et al., 1994b; Muris et al., 1995c; van Zuuren, 1993, 1994). They have also tended to involve mildly to moderately stressful laboratory tasks (Miller, 1987; Muris et al., 1994d; Muris, Van Zuuren, & Merckelbach, 1993b) and single-session medical or dental procedures or treatments of limited duration (Andrykowski et al., 2002; Miller et al., 1988; Miller & Mangan, 1983; Miller et al., 1994).

Past research investigating the experience of chemotherapy treatment has assessed outcomes before treatment and after the first few treatments (Gard et al., 1988; Lerman

et al., 1990; McKinnon, 2001; Shapiro et al., 1997). Typically, the research has reported declines in physical and psychological wellbeing at the beginning (McKinnon, 2001; Shapiro et al., 1997) or at an arbitrary time during chemotherapy treatment (Gard et al., 1988). The research has not investigated outcomes throughout treatment and/or included a substantial follow-up period. The present study enabled an understanding of the medium- to long-term effects of monitoring and blunting coping in the experience of a significantly large sample of women undergoing chemotherapy. The intensive assessment of wellbeing in the present study suggests that the previous estimates of physical and psychological wellbeing during chemotherapy treatment do not capture the variations in wellbeing experience. It is essential that future research employs a similarly intensive and long-term assessment of wellbeing during and following chemotherapy in order to continue to advance understanding of this challenging treatment.

The research provided considerable information regarding the nature of the relationships between monitoring and blunting coping and the experience of anxiety, depression and side effects in response to chemotherapy. It is one of few studies that has investigated both physical and psychological wellbeing experienced in response to a stressful medical procedure or treatment (Lerman et al., 1990; Manne et al., 2001; McKinnon, 2001; Shapiro et al., 1997). Other studies have focused on either physical wellbeing (Gard et al., 1988; Muris & Van Zuuren, 1992; Steptoe & Noll, 1997) or psychological wellbeing (Andrykowski et al., 2002; Miller et al., 1994; Miller et al., 1995; Schwartz et al., 1995).

Furthermore, the study investigated the relationships between monitoring and blunting coping and locus of control beliefs and risk perceptions of a future recurrence. These constructs have been consistently linked with coping styles in the theory but to date only limited research has been conducted on coping styles and locus of control beliefs (Hack & Degner, 1999; Muris et al., 1995b; van Zuuren & Wolfs, 1991) and risk perception (Fang et al., 2002; Schwartz et al., 1995). Clarification of the role of coping styles in locus of control beliefs and risk perception is important as locus of control beliefs and risk perception significantly determine people's desired role in health care decision-making (Helmets et al., 2002), performance of health promotion and disease prevention behaviours (Aro et al., 1999; Borrayo & Guarnaccia, 2000; Bundek et al.,

1993; Fajardo et al., 1992; Franco et al., 2000; Glenn & Moore, 1990; Murray & McMillan, 1993; Patterson et al., 2003) and psychological wellbeing in survivorship (Curran et al., 1998; Dow et al., 1996; Johnson Vickberg, 2001; Kissane et al., 1997; Tomich & Helgeson, 2002; Wenzel et al., 1999), all of which are important in ensuring physical and psychological wellbeing during and following treatment.

The study is the first of its kind in accounting for a wide range of demographic, health, disease and treatment characteristics in the experience of chemotherapy treatment. Inclusion of these characteristics in the analyses ensured that the variance accounted for by coping styles in physical and psychological wellbeing and locus of control beliefs and risk perceptions was accurately detected. In so doing, the statistically significant and sizeable roles of coping styles in the levels of anxiety, depression, side effects, locus of control beliefs and, to a lesser extent, risk perception reported were made apparent. Further research is needed to replicate these findings.

The importance of considering demographic, health, disease and treatment characteristics in the analyses was also evident in that the characteristics had significant and small roles in the levels of anxiety, depression, side effects, locus of control beliefs and risk perception. The failure of past research to consider these variables in assessing physical and psychological wellbeing may mean the findings reported are misleading (Gard et al., 1988; McKinnon, 2001; Shapiro et al., 1997). The significant roles of monitoring and blunting coping in regards to physical and wellbeing reported in the present study may signal that the past research has underestimated the importance of coping styles in wellbeing in patients facing stressful medical procedures or treatments. Future research investigating the role of the coping styles in cancer patients must therefore ensure that these variables are included.

The presented study also offered a range of clinical implications, the first of which concern doctor-patient decision-making and relationships during treatment. The study confirmed the theory that coping styles are associated with locus of control beliefs (Miller, 1996; Miller et al., 1993). Past research has suggested that these beliefs have an important influence over the desired role of patients in health care decision-making. For example, patients with stronger internal locus of control beliefs desire a more active role

in decision-making than those with stronger chance and powerful others locus of control beliefs (Helmes et al., 2002).

Ensuring that patients experience good relationships with medical professionals and are satisfied with their role in decision-making are crucial. Patients who experience good relationships with their medical professionals and are satisfied with their role in decision-making have been shown to report less distress several months post-diagnosis (Breaden, 1997; Ganz et al., 2004; Lethborg et al., 2000; Ong et al., 2000; Vivar & McQueen, 2005; Wyatt et al., 1993). Understanding the relationships between coping styles and locus of control beliefs may enable doctors to more effectively tailor their consultations to suit the desired role of patients and thus strengthen their relationships with patients. This will preserve patients' psychological wellbeing in the long-term.

The information regarding the variation in experience of anxiety, depression and side effects before, during and six months following chemotherapy treatment also has the potential to affect decision-making and doctor-patient relationships. The study provides important information regarding the levels of anxiety, depression and side effects experienced during and following chemotherapy as well as the way in which demographic, disease and surgical and chemotherapy treatment characteristics affect the levels of anxiety, depression and side effects. Providing medical professionals with this knowledge ensures that they are better able to provide patients with accurate and detailed expectations about the effect of chemotherapy on physical and psychological wellbeing. This enables patients make an informed choice regarding cancer treatment options and in cases where patients do chose to undergo chemotherapy treatment, medical professionals are better able to prepare them for what to expect. The benefits of which are good relationships between medical professionals and patients, a high degree of patient satisfaction with decision-making role and future psychological wellbeing.

Of great interest was the finding that coping styles were implicated in the experience of anxiety, depression and side effects experienced before, during and six months following chemotherapy treatment. An understanding of the way in which coping styles affect physical and psychological wellbeing means that medical professionals and psychologists may be able to screen patients to identify those at risk of poorer physical and psychological wellbeing. In the case of medical professionals, this is of particular

importance as they have demonstrated difficulty identifying patients experiencing elevated levels of anxiety and depression (Badger et al., 2004; Berard et al., 1998; Nordin et al., 2001; Payne et al., 1999).

Once at-risk patients are identified, medical professionals and psychologists may offer appropriate support to prevent or ameliorate declines in physical and psychological wellbeing. This might involve regular check-ups regarding patients' levels of psychological distress and the provision of support to reduce distress. This may serve to prevent the likelihood of developing or continued experience of poor physical and psychological wellbeing after treatment. Research has demonstrated that women with breast cancer who report experiencing anxiety and/or depression at diagnosis are significantly more likely to experience anxiety and depression six to twelve months later (Nordin et al., 2001; Schou et al., 2004).

For medical professionals, this may involve finely tuning the chemotherapy regimen and supportive treatment offered to patients to ensure patients' physical wellbeing is preserved. For example, it was found that Taxol was associated with increased side effects. It may be that Taxol is an inappropriate regimen for patients employing a coping style that places them at risk of developing significant side effects. Instead, medical professionals may be able to offer an equally effective yet less toxic regimen. Medical professionals may also be able to offer more or stronger supportive medications to reduce the severity and impact of side effects. For example, patients at risk of experiencing elevated side effects may be prescribed stronger anti-emetic medication or offered GCSF support.

The benefits of effectively controlling side effects are considerable. Patients with fewer side effects may report greater levels of physical functioning and psychological wellbeing. They may also be less likely to experience medical complications requiring intensive and expensive medical treatment. For example, patients experiencing significant side effects are frequently at risk of developing neutropenia, a condition which often requires increased use of anti-emetic, the addition of GCSF to future chemotherapy treatments and hospitalisation. Such medical complications are distressing to patients and greatly increase the economic cost of cancer treatment

(AIHW & AACR, 2004; NHMRC & NBCC, 2001; Rhew, Young, & Goetz, 2001; Tucker et al., 2001).

In regards to the role of psychologists, interventions aimed at reducing the use of coping styles associated with poorer physical and psychological wellbeing may be designed and implemented in the future. Research has demonstrated that it is possible to alter people's coping styles. The present study showed that participants' reported use of coping styles changed over time and past research has shown that people can be successfully instructed to utilise coping styles different from their preferred style (Muris et al., 1994a; Muris et al., 1995b). Such interventions may reduce the likelihood of experiencing elevated levels of anxiety, depression and side effects in the period following chemotherapy. Research has demonstrated that the likelihood of poor physical and psychological wellbeing during survivorship is increased when poor wellbeing is experienced during diagnosis and treatment (Beisecker et al., 1997; Bower et al., 2000; Castellon et al., 2005; de Jong et al., 2002b; Falletti et al., 2005; Frost et al., 2000; Jansen et al., 2005; NHMRC & NBCC, 2001; Nordin et al., 2001; Sadler & Jacobsen, 2001; Schagen et al., 1999; Schou et al., 2004). Maintaining good physical and psychological wellbeing may ensure the continued compliance of patients with treatment.

The few interventions carried out to date have reported limited success in improving psychological wellbeing in the short and medium term. Many of the interventions consist of the provision of components of cognitive-behavioural therapy (Burish et al., 1991; Edelman et al., 1999; Lerman et al., 1990; Morgenstern et al., 1984), a psychotherapy that has been shown to be effective at treating mood disorders but not necessarily in cancer patients (Nathan & Gorman, 2002). The limited success of these interventions is no doubt due to the fact that they have not been strongly based on the empirical literature regarding cancer patients. The present study signals an attempt to develop an empirical base that outlines the way in which coping styles may affect physical and psychological wellbeing, with the view to designing interventions aimed at improving physical and psychological wellbeing in cancer patients in the short- and medium-term. In fact, some research has already demonstrated that interventions aimed at altering coping styles in order to affect wellbeing are successful, although these have not yet been conducted on cancer patients (Muris et al., 1994a; Muris et al., 1995b).

The study also provided new evidence regarding risk perception of breast cancer recurrence. Recent research has indicated that risk of recurrence is the greatest concern of breast cancer survivors and the perception of high risk is strongly associated with psychological distress (Curran et al., 1998; Dow et al., 1996; Johnson Vickberg, 2001; Kissane et al., 1997; Tomich & Helgeson, 2002; Wenzel et al., 1999). Again, coping styles were implicated in participants' perceived risk estimates with those using the blunting coping style reporting lower estimates of personal perceived risk. Future research may be able to verify these results and if so, knowledge of the way in which coping styles affect perceived risk may enable psychologists to develop and implement interventions designed to improve the accuracy of perceived risks via the use of particular coping styles.

This is a worthy avenue of future research and practice, given that recent interventions aimed at altering perceived risks via education about actual risks have not been effective. Indeed, it has been suggested that risk perception is influenced by psychological factors (Kent et al., 2000; Weinstein et al., 2004), of which coping styles may be one. The importance of holding accurate risk estimates and dealing with the associated distress is clear. Recent research has shown that perceived risk estimates are significantly associated with elevated levels of distress (Cunningham et al., 1998; Kent et al., 2000) and engagement in appropriate health promotion and disease preventive behaviours, which are important to survival (Bowen et al., 2003; Gil et al., 2003).

Similarly, coping styles were implicated in cancer-specific locus of control beliefs. Past research has also shown that locus of control beliefs affect engagement in health promotion and disease prevention behaviours. Patients with more internal locus of control beliefs are more likely to engage in breast cancer screening and healthy lifestyle behaviours than those with more chance and powerful others locus of control beliefs (Aro et al., 1999; Borrayo & Guarnaccia, 2000; Bundek et al., 1993; Fajardo et al., 1992; Franco et al., 2000; Glenn & Moore, 1990; Murray & McMillan, 1993; Patterson et al., 2003; van Zuuren & Dooper, 1999). For women recently completing active treatment for breast cancer, successful survival involves participation in regular check-ups and screening and for some, taking endocrine therapy each day (ATACTG, 2002, 2003; NHMRC & NBCC, 2001). Women's coping styles may serve to identify those at

risk of not complying with the follow-up screening and treatment and may provide psychologists with opportunities for intervention.

The coping styles of monitoring and blunting appear to play a key role in the experience of adjuvant chemotherapy in women diagnosed with EBC. The exploratory nature of the present study has highlighted the potential for coping styles to affect all stages of chemotherapy treatment, from treatment decision-making to preparation, from receipt of chemotherapy to recovery. With the assistance of further research, understanding the nature and broad influence of monitoring and blunting coping styles may indicate the possibilities for improving women's physical and psychological wellbeing throughout and following chemotherapy treatment. The ability to intervene and improve medical and psychosocial outcomes during and following chemotherapy treatment may have profound effects on the physical and psychological wellbeing of the many women diagnosed with breast cancer each year in Australia.

APPENDIX A

Threatening Medical Situations Inventory (van Zuuren et al., 1996)

Below are descriptions of situations you might have found yourself in or can imagine finding yourself in. Each situation is followed by several statements of the things you might think or do in that situation. Please indicate for each statement the degree to which it applies to you.

1. Imagine you have been suffering from headaches and dizziness for some time. When you visit your doctor, he/she tells you things don't look too good and refers you to a specialist for a rather difficult medical examination.

Please indicate for each statement below to what degree it is applicable to you, by circling your answer.

- 1 = not at all applicable to me
- 2 = not very much applicable to me
- 3 = a bit applicable to me
- 4 = rather applicable to me
- 5 = strongly applicable to me

- | | | | | | |
|---|---|---|---|---|---|
| 1a) I plan to ask the specialist as many questions as possible. | 1 | 2 | 3 | 4 | 5 |
| b) I think things will turn out to be alright. | 1 | 2 | 3 | 4 | 5 |
| c) I am determined to get more information from other health centres. | 1 | 2 | 3 | 4 | 5 |
| d) I plan to start reading about headaches and dizziness. | 1 | 2 | 3 | 4 | 5 |
| e) For the time being I try not to think of unpleasant outcomes. | 1 | 2 | 3 | 4 | 5 |
| f) I am not going to worry: such an examination is not as bad as suffering from headaches all the time. | 1 | 2 | 3 | 4 | 5 |

2. Imagine you work very hard and you are overweight. Your doctor has explained to you that this is unwise. During a check-up, he/she tells you that you have high blood pressure.

2a) I look at the blood pressure monitor in order to ensure he is not mistaken.

1 2 3 4 5

b) I try to take things easy.

1 2 3 4 5

c) I decide to live on normally.

1 2 3 4 5

d) I ask him extensively about the risks and consequences involved.

1 2 3 4 5

e) I tell myself some medical problems are worse than this one.

1 2 3 4 5

f) I plan to start reading a lot about high blood pressure.

1 2 3 4 5

3. Imagine you have heart problems. Your specialist advises you to have an operation. He/she tells you that you will have to wait four months for it and that he/she is not certain whether the operation will be effective.

3a) I take the line that, in my case, the operation will be effective.

1 2 3 4 5

b) I decide to go deeply into all that is known about heart surgery.

1 2 3 4 5

c) I decide to undertake as many pleasant and useful activities as possible for the next few months.

1 2 3 4 5

d) I decide to find out whether there is a chance that the operation will make things worse.

1 2 3 4 5

e) I decide to contact other patients with the same medical problem, for information.

1 2 3 4 5

f) I tell myself 'things will turn out to be alright'.

1 2 3 4 5

4. Imagine, you visit your doctor because you are having some bowel problems. He/she diagnoses you with acute appendicitis and tells you that you have to have an operation in the hospital as soon as possible.

4a) I tell him I want to know precisely what they are going to do with me.

1 2 3 4 5

b) I decide to relax now in the face of what is coming over me.

1 2 3 4 5

c) I ask myself whatever can go wrong.

1 2 3 4 5

d) I take things easy.

1 2 3 4 5

e) I tell myself ‘things will turn out to be alright’.

1 2 3 4 5

f) I immediately try to call somebody who may inform me about this operation.

1 2 3 4 5

APPENDIX B

Miller Behavioural Style Scale (Miller, 1987)

Below are descriptions of situations you might have found yourself in or can imagine finding yourself in. Each situation is followed by several statements of the things you might think or do in that situation. Please indicate for each statement below to what degree it is applicable to you, by circling your answer:

- 1 = not at all applicable to me
- 2 = not very much applicable to me
- 3 = a bit applicable to me
- 4 = rather applicable to me
- 5 = strongly applicable to me

1. Vividly imagine that you are afraid of the dentist and have to get some dental work done.

- a) I would plan to ask the dentist exactly what he was going to do.

12345
- b) I would take a tranquilliser or have a drink before going.

12345
- c) I would try to think about pleasant memories.

12345
- d) I would want the dentist to tell me when I would feel pain.

12345
- e) I would try to sleep or switch off from what was happening.

12345
- f) I would watch all the dentist's movements and listen for the sound of the drill.

12345
- g) I would watch the flow of the water from my mouth to see if it contained blood.

12345
- h) I would do mental puzzles in my mind or think of other things.

12345

2. Vividly imagine that, due to a large drop in sales, it is rumoured that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about lay-offs has been made and will be announced in several days.

a) I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said.

1 2 3 4 5

b) I would review the list of duties for my present job and try to figure out if I had fulfilled them all.

1 2 3 4 5

c) I would go to the movies to take my mind off things.

1 2 3 4 5

d) I would try to remember any arguments or disagreements I might have had with my supervisor that would have lowered his/her opinion of me.

1 2 3 4 5

e) I would push all thoughts of being laid off out of my mind.

1 2 3 4 5

f) I would tell my spouse that I'd rather not discuss my chances of being laid off.

1 2 3 4 5

g) I would try to think of which employees in my department the supervisor might have thought had done the worst job.

1 2 3 4 5

h) I would continue doing my work as if nothing special was happening.

1 2 3 4 5

3. Vividly imagine that you are on an aeroplane, 30 minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be tough. You, however, are not convinced that all is well.

a) I would carefully read the information provided about safety in the plane and make sure I knew where the emergency exists were. 1 2 3 4 5

1 2 3 4 5

b) I would make small talk with the passenger beside me.

1 2 3 4 5

c) I would watch the end of the movie, even if I had seen it before.

1 2 3 4 5

d) I would call for the steward/stewardess and ask him/her exactly what the problem was.

1 2 3 4 5

e) I would order a drink from the steward/stewardess.

1 2 3 4 5

f) I would listen carefully to the engines for unusual noises and would watch the crew to see if their behaviour was out of the ordinary.

1 2 3 4 5

g) I would talk to the passenger beside me about what might be wrong.

1 2 3 4 5

h) I would settle down and read a book or magazine, or write a letter.

1 2 3 4 5

4. Vividly imagine that you are being held hostage by a group of armed terrorists in a public building.

a) I would sit by myself and think about other things as much as I could.

1 2 3 4 5

b) I would stay alert and try to keep myself from falling asleep.

1 2 3 4 5

c) I would exchange life stories with other hostages.

1 2 3 4 5

d) If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing.

1 2 3 4 5

e) I would watch every move of my captors and keep an eye on their weapons.

1 2 3 4 5

f) I would try to sleep or relax as much as possible.

1 2 3 4 5

g) I would think about how nice it's going to be when I get home.

1 2 3 4 5

h) I would make sure I knew where every possible exit was.

1 2 3 4 5

APPENDIX C

Impact of Events Scale (Horowitz et al., 1979)

Below is a list of comments made by people after stressful life events such as chemotherapy treatment for cancer. Please circle the response indicating how frequently these comments were true **during the past seven days**. If they did not occur at all, please mark 1 (Not at all).

1 = Not at all

2 = Rarely

3 = Sometimes

4 = Often

I thought about it when I did not mean to.	1	2	3	4
I avoided letting myself get upset when I thought about it or was reminded of it.	1	2	3	4
I tried to remove it from my memory.	1	2	3	4
I had trouble falling asleep or staying asleep because of pictures or thoughts about it that came to mind.	1	2	3	4
I had waves of strong feelings about it.	1	2	3	4
I had dreams about it.	1	2	3	4
I stayed away from reminders about it.	1	2	3	4
I felt as if it hadn't happened or it wasn't real.	1	2	3	4
I tried not to talk about it.	1	2	3	4
Pictures of it popped into my mind.	1	2	3	4
Other things kept making me think about it.	1	2	3	4
I was aware that I still had a lot of feelings about it, but I didn't deal with them.	1	2	3	4
I tried not to think about it.	1	2	3	4
Any reminder brought back feelings about it.	1	2	3	4
My feelings about it were kind of numb.	1	2	3	4

APPENDIX D

Multidimensional Health Locus of Control Scale (Wallston et al., 1994)

For each statement please indicate whether you agree or not by circling the appropriate number. The numbers represent these attitudes:

- | | | | |
|---|-------------------|---|----------------|
| 1 | strongly disagree | 4 | slightly agree |
| 2 | somewhat disagree | 5 | somewhat agree |
| 3 | slightly disagree | 6 | strongly agree |

Circle only one number, the one which is closest to your feeling. Please answer every question.

1. If my health worsens, it is my own behaviour which determines how soon I will be better again.

1 2 3 4 5 6

2. I am directly responsible for my health getting better or worse.

1 2 3 4 5 6

3. Whatever goes wrong with my health is my fault.

1 2 3 4 5 6

4. The main thing which affects my health is what I myself do.

1 2 3 4 5 6

5. If my health takes a turn for the worse, it is because I have not been taking proper care of myself.

1 2 3 4 5 6

6. I deserve the credit when my health improves and the blame when it gets worse.

1 2 3 4 5 6

7. Most things that affect my health happen to me by chance.

1 2 3 4 5 6

8. Luck plays a big part in determining how my health improves.

1 2 3 4 5 6

9. Whatever improvement occurs with my health is largely a matter of good fortune.

1 2 3 4 5 6

10. If my health worsens, it's a matter of fate.

1 2 3 4 5 6

11. If I am lucky, my health will get better.

1 2 3 4 5 6

12. As to my health, what will be will be.

1 2 3 4 5 6

13. If I see my doctor regularly, I am less likely to have problems with my health.

1 2 3 4 5 6

14. Following doctor's orders to the letter is the best way to keep my health from getting worse.

1 2 3 4 5 6

15. Whenever my health worsens, I should consult a medically trained professional.

1 2 3 4 5 6

16. Other people play a big role in whether my health improves, stays the same, or gets worse.

1 2 3 4 5 6

17. The type of help I receive from other people determines how soon my health improves.

1 2 3 4 5 6

18. In order for my health to improve, it is up to other people to see that the right thing happen.

1 2 3 4 5 6

APPENDIX E

APPENDIX F

Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983)

Below are some statements about how you have been feeling over the past week. Please choose one response from the four given by placing a tick next to the response. Try not to think too long about your answers and just give your immediate response.

I feel tense or wound up

- ☐ Most of the time
- ☐ A lot of the time
- ☐ From time to time, occasionally
- ☐ Not at all

I still enjoy the things I used to enjoy

- ☐ Definitely as much
- ☐ Not quite so much
- ☐ Only a little
- ☐ Hardly at all

I get a sort of frightened feeling as if something awful is about to happen

- ☐ Very definitely and quite badly
- ☐ Yes, but not too badly
- ☐ A little, but it doesn't worry me
- ☐ Not at all

I can laugh and see the funny side of things

- ☐ As much as I always could
- ☐ Not quite so much now
- ☐ Definitely not so much now
- ☐ Not at all

Worrying thoughts go through my mind

- ☐ A great deal of the time
- ☐ A lot of the time
- ☐ From time to time, occasionally
- ☐ Only occasionally

I feel cheerful

- _____ Not at all
- _____ Not often
- _____ Sometimes
- _____ Most of the time

I can sit at ease and feel relaxed

- _____ Definitely
- _____ Usually
- _____ Not often
- _____ Not at all

I feel as if I have slowed down

- _____ Nearly all the time
- _____ Very often
- _____ Sometimes
- _____ Not at all

I get a sort of frightened feeling like “butterflies” in the stomach

- _____ Not at all
- _____ Occasionally
- _____ Quite often
- _____ Very often

I have lost interest in my appearance

- _____ Definitely
- _____ I don’t take as much care as I should
- _____ I may not take quite as much care
- _____ I take just as much care as ever

I feel restless as I have to be on the move

- _____ Very much indeed
- _____ Quite a lot

_____ Not very much
 _____ Not at all

I look forward with enjoyment to things

_____ As much as I ever did
 _____ Rather less than I used to
 _____ Definitely less than I used to
 _____ Hardly at all

I get sudden feelings of panic

_____ Very often
 _____ Quite often
 _____ Not very often
 _____ Not at all

I can enjoy a good book or radio or TV program

_____ Often
 _____ Sometimes
 _____ Not often
 _____ Seldom

APPENDIX G

Chemotherapy Side Effects Scale

Many people undergoing similar treatment to you have had some of the following symptoms or concerns at different times, and to varying degrees of severity. We would like you to tell us whether you have experienced any of the following symptoms in the last 7 days. Please indicate how severe those symptoms have been during that time by placing a tick next to the response that best describes your symptoms.

1. Lack of Energy

- ☐ I did not feel any more tired than usual
- ☐ I felt a little tired
- ☐ I felt moderately tired
- ☐ I felt very tired and found it difficult to do everyday activities/tasks
- ☐ I felt so tired that I could not look after myself

2. Lack of Appetite

- ☐ My appetite was the same as usual
- ☐ I felt less hungry than usual
- ☐ I felt less hungry than usual and was eating less than normal
- ☐ I did not feel hungry and lost weight
- ☐ I could not eat anything

3. Pain

- ☐ I had no pain at all
- ☐ I was in some pain
- ☐ I was in moderate pain
- ☐ I was in a lot of pain and found it difficult to do everyday activities/tasks
- ☐ I was in so much pain that I could not look after myself

4. Constipation

- ☐ I was not constipated
- ☐ I have been constipated at times
- ☐ I have been constipated most days
- ☐ I was so constipated that I found it difficult to do everyday activities/tasks
- ☐ I was so constipated that I could not do anything

5. Nausea

- _____ I did not feel nauseous
- _____ I felt nauseous but I managed to eat normally
- _____ I felt nauseous and I was eating less than usual
- _____ I felt so nauseous that I was eating less than usual and have lost some weight
- _____ I felt so nauseous that I could not eat at all and have lost weight

6. Vomiting

- _____ I did not vomit
- _____ I vomited about once on one or more days
- _____ I vomited 2-5 times on one or more days
- _____ I vomited 6 or more times on one or more days
- _____ I could not stop vomiting and needed medical assistance

7. Difficulty Sleeping

- _____ I have had no problems sleeping
- _____ I found it difficult to sleep at times
- _____ I found it difficult to sleep most nights
- _____ I cannot sleep and am finding it difficult to do everyday activities/tasks
- _____ I cannot sleep and cannot look after myself

8. Shortness of Breath

- _____ I did not have difficulty breathing
- _____ I found it difficult to breath when I tried to do something
- _____ I found it so difficult to breath when I did something that I needed to take a break
- _____ I found it so difficult to breath that I could not look after myself
- _____ I found it difficult to breath even when I was not doing anything

9. Dizziness

- _____ I did not feel dizzy
- _____ I felt dizzy when I moved my head
- _____ I felt dizzy and found it difficult to do some things

_____ I felt so dizzy I could not do everyday activities/tasks

_____ I felt so dizzy I could not do anything for myself

10. Sore Muscles

_____ My muscles did not feel sore

_____ My muscles felt a little sore

_____ My muscles felt moderately sore

_____ My muscles felt very sore

_____ My muscles felt so sore I could not do anything

11. Problems Remembering Things / Memory Problems

_____ I have not noticed any problems with my memory

_____ I have had some problems remembering things

_____ I have had moderate problems remembering things

_____ My memory problems made it difficult to do everyday activities/tasks

_____ I have difficulty remembering anything

12. Coughing

_____ I have not been coughing any more than usual

_____ I have been coughing at times

_____ I have coughed so much that I needed some medication

_____ I have been coughing so much that I find it difficult to sleep or do everyday activities/tasks

APPENDIX H



AUSTRALIAN NATIONAL UNIVERSITY

ARCH SERVICES OFFICE

n Ethics Officer
Deutsch

CANBERRA ACT 0200 AUSTRALIA

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EMAIL: Sylvia.Deutsch@anu.edu.au

May 2003

Ms Sarah Davenport
Postgraduate Student
School of Psychology
Faculty of Science
The Australian National University ACT 0200

Ms Davenport,

Protocol 2003/55
Coping styles and the experience of chemotherapy

On behalf of the Human Research Ethics Committee I am pleased to advise that the above protocol has been approved as per the attached *Outcome of Consideration of Protocol*. Please note that as a formality this approval is subject to formal ratification by the Committee at its next meeting on 30 May 2003.

For your information:

Under the NHMRC/AVCC *National Statement on Ethical Conduct in Research Involving Humans* we are required to follow up research that we have approved. Once a year (or sooner for short projects) we shall request a brief report on any ethical issues which may have arisen during your research and whether it proceeded according to the plan outlined in the above protocol.

Please notify the Committee of any changes to your protocol in the course of your research, and when you complete or cease working on this project.

The validity of this current approval is five years' maximum from the date shown on the attached *Outcome of Consideration of Protocol* form. For longer projects you are required to seek renewed approval from the Committee.

Yours sincerely,

Sylvia Deutsch

Sylvia Deutsch

Secretary, Human Research Ethics Committee



***ACT HEALTH AND COMMUNITY CARE
HUMAN RESEARCH ETHICS COMMITTEE***

Ms Monica Skjerve
School of Psychology
Building 39
Australian National University
CANBERRA ACT 0200

Dear Ms Skjerve

Thank you for your letter of 10 November 2003 addressing concerns raised by the Committee at the meeting held 20 October 2003, in respect of the proposed study 'Coping Styles and Severity of Toxicity from Adjuvant Chemotherapy for Early Breast Cancer and Colo-Rectal Cancer'. Ethics Committee Submission No ETH.7/03.317 refers.

I am pleased to advise you that the study has now been approved, including the letter 'Coping with Chemotherapy'. Patient Information Sheet, Consent Form and Questionnaire.

I attach for your records an Outcome of Consideration of Protocol form.

You may recall that the ACT Health and Community Care Guidelines for Submission of Application require you to complete payment of the levy when approved by the Ethics Committee.

Please forward \$27.50 levy fee to the Secretariat, ACT Health and Community Care Human Research Ethics Committee, GPO Box 825, Canberra ACT 2601 as soon as possible. An invoice is attached for your attention.

I confirm that the ACT Health and Community Care Human Research Ethics Committee is constituted according to the National Health and Medical Research Council Guidelines and operates in compliance with applicable regulatory requirements and the International Conference on Harmonization Guidelines on Good Clinical Practice.

Yours sincerely

Elizabeth Grant AM
Chair
Ethics Committee
11 November 2003

Friday, 18th June 2004

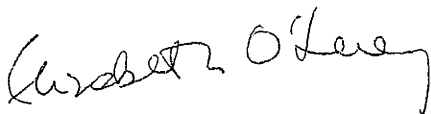
Ms Sarah Davenport
PhD Candidate
School of Psychology
Building 39
ANU
CANBERRA ACT 0200

Dear Ms Davenport

I am pleased to advise that the Executive Management Group has approved the case study proposal *"Coping Styles and Severity of Toxicity from Adjuvant Chemotherapy for Early Breast Cancer and Colo-Rectal Cancer"* on the recommendation of the Human Research and Ethics Committee, which met on Wednesday, 5th May 2004.

The Committee would appreciate a regular update and a report on completion of the study. Should you wish to publish your project and Calvary Health Care is in any way identified, the Committee wishes to approve the paper prior to publication.

Sincerely



Elizabeth O'Leary
REC Chairperson

Calvary Health Care
ACT Limited
ABN 74 105 304 989

PO Box 254
Jamison Centre
ACT 2614
www.calvary-act.com.au

LOCATIONS

Calvary Public Hospital
Calvary Private Hospital
Calvary Clinic
Calvary Foundation
Cnr Belconnen Way
and Haydon Drive
Bruce ACT 2617

Clare Holland House
(ACT Hospice)
Menindee Drive
Barton ACT 2600
Ph: 02 6273 0336
Fax: 02 6273 0338

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Healthscope Limited ABN 85 006 405 152

3 March 2004

Ms Sarah Davenport
PhD Candidate
School of Psychology
The Australian National University
CANBERRA ACT 0200

Dear Ms Davenport,

Thank you for your letter of 13 February to David Maruskanic regarding the research project *Coping with Chemotherapy in Women with Breast or Colorectal Cancer*. I have now taken on the position of General Manager at National Capital Private.

We are happy to be involved in the project given your ACT Human Research Ethics Committee approval. I have passed on your letter to Kim McGovern our Day Chemotherapy Unit Manager. Kim will be able to provide you with any assistance you require for the trial.

We look forward to being involved in your research trial. If you have any questions don't hesitate to contact me on 6222 6602.

Yours sincerely



Paul Waterson
General Manager/Director of Nursing



John James
Memorial Hospital

February 2004

Strickland Crescent, Deakin, ACT, 2600
PO Box 23, Deakin West, ACT, 2600
Telephone (02) 6281 8100
Facsimile (02) 6281 8168

Sarah Davenport
School of Psychology Building 39
Australian National University
Canberra ACT 0200

Ms Davenport

Application to conduct research in the "Coping Styles and Severity of Toxicity from Adjuvant
Chemotherapy for Early Breast Cancer and Colo/Rectal cancer"

John James Memorial Hospital Ethics Committee, at its meeting on 5 February 2004, considered
the above application, and approved the study as presented.

Yours sincerely

Noel P. Faunce
Chairman
Ethics Committee
John James Memorial Hospital

APPENDIX I

Information Sheet for Participants Attending The Canberra Hospital, The National
Capital Hospital, and John James Memorial Hospital

Coping Styles and the Experience of Chemotherapy
Patient Information Sheet

Each year, many people are diagnosed with cancer and for many of them, chemotherapy is recommended. Chemotherapy can produce a number of side effects. Research has shown that in order to deal with this treatment, patients use many varied ways of coping. The purpose of this project is to investigate how people cope with chemotherapy and whether a particular way of coping with chemotherapy is associated with enhanced emotional and physical well-being.

As you are undergoing chemotherapy for breast or colo/rectal cancer we invite you to participate in this project. Participation involves filling out a number of questionnaire packages. These will be filled out before starting chemotherapy, after the first 3-4 chemotherapy treatments, on completion, and six months and one year after the completion of chemotherapy treatment. The questionnaires will ask you to consider the way in which you deal with stressful situations and your emotional wellbeing. You may complete the questionnaires in your own time and return them to the research group in the stamped, self-addressed envelopes provided. Alternatively, we can assist with the completion of the questionnaire if this is preferable. Each questionnaire will take 30-60 minutes to complete.

In addition, we will require information about your medical history before starting chemotherapy, during chemotherapy and, six months and one year following the completion of chemotherapy. The information we are interested in includes the standard tests and information your Oncologist will collect as part of routine medical procedure. We ask that we can look at your medical records to collect this information. We will record any information from your medical records using your code number, not your name. No medical tests will be done that would not be routinely done as part of your medical care.

Your participation in this study is voluntary. You can decline to participate in this study at any time, without reason. Your decision to participate or not in this study will not affect your medical care **in any way**. If you choose to withdraw from the study, any previously completed documents will be destroyed.

Your participation is also confidential. All questionnaires and medical information we collect will be kept in a locked cabinet which can only be accessed by the research group. Moreover, none of the questionnaires and medical information will have your name written on them. You will be given a code number that will be used to identify your questionnaires and medical information. A sheet which matches your name and code number will be kept in a separate locked cabinet which again, only the research group can access. On completion of the study, forms containing contact details will be destroyed. The project has been approved both by the ACT Health Human Research Ethics Committee and the Australian National University Human Research Ethics Committee.

If you have any questions regarding any of the information covered in this sheet or about the research in general, please do not hesitate to contact either of the following researchers or the ACT Health and Community Care Human Research Ethics Committee:

A/Prof Robin Stuart-Harris
Medical Oncology Unit
The Canberra Hospital
Yamba Drive
Garran ACT 2605
Ph: (02) 6244 2220
Email: Robin.Stuart-Harris@act.gov.au

Ms Sarah Davenport
School of Psychology
Building 39
The Australian National University
Canberra ACT 0200
Ph: (02) 6125 2147
Email: Sarah.Davenport@anu.edu.au

Professor Don Byrne
School of Psychology
Building 39
The Australian National University
Canberra ACT 0200

The Human Ethics Officer
The Australian National University
Canberra ACT 0200

Ph: (02) 6125 3974

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Ph: (02) 6125 7945

Email:human.research.officer@anu.edu.au

ACT Community Care Human Research Ethics Committee

Secretary

Second Floor, North Building

London Circuit

Canberra City ACT 2601

Ph: (02) 6205 0846

The ACT Government Homepage is <http://www.act.gov.au>

APPENDIX J

Patient Information Sheet for Participants Attending Calvary Hospital

Coping Styles and the Experience of Chemotherapy

Patient Information Sheet

Each year, many people are diagnosed with cancer and for many of them, chemotherapy is recommended. Chemotherapy can produce a number of side effects. Research has shown that in order to deal with this treatment, patients use many varied ways of coping. The purpose of this project is to investigate how people cope with chemotherapy and whether a particular way of coping with chemotherapy is associated with enhanced emotional and physical well-being.

As you are undergoing chemotherapy for breast or colo/rectal cancer we invite you to participate in this project. Participation involves filling out a number of questionnaire packages. These will be filled out before starting chemotherapy, after the first 3-4 chemotherapy treatments, on completion of chemotherapy treatment, and one year after the completion of chemotherapy treatment. The questionnaires will ask you to consider the way in which you deal with stressful situations and your emotional wellbeing. You may complete the questionnaires in your own time and return them to the research group in the stamped, self-addressed envelopes provided. Alternatively, we can assist with the completion of the questionnaire if this is preferable. Each questionnaire will take 30-60 minutes to complete.

In addition, we will require information about your medical history before starting chemotherapy, during chemotherapy and one year following the completion of chemotherapy. The information we are interested in includes the standard tests your Oncologist will collect as part of routine medical procedure. We will ask your Oncologist to pass on this information to us so the researcher will not have to look at your medical records. Your Oncologist will provide us with this information using your code number, not your name. No medical tests will be done that would not be routinely done as part of your medical care.

Your participation in this study is voluntary. You can decline to participate in this study at any time, without reason. Your decision to participate or not in this study will not

affect your medical care **in any way**. If you choose to withdraw from the study, any previously completed documents will be destroyed.

Your participation is also confidential. All questionnaires and medical information we collect will be kept in a locked cabinet which can only be accessed by the research group. Moreover, none of the questionnaires and medical information will have your name written on them. You will be given a code number that will be used to identify your questionnaires and medical information. A sheet which matches your name and code number will be kept in a separate locked cabinet which again, only the research group can access. On completion of the study, forms containing contact details will be destroyed. The project has been approved both by the Medico Moral, Human Research and Ethics Committee (MMHREC) and the Australian National University Human Research Ethics Committee.

If you have any questions regarding any of the information covered in this sheet or about the research in general, please do not hesitate to contact either of the following researchers or the Medico Moral, Human Research and Ethics Committee (MMHREC):

A/Prof. Robin Stuart-Harris
 Medical Oncology Unit
 The Canberra Hospital
 Yamba Drive
 Garran ACT 2605
 Ph: (02) 6244 2220
 Email: Robin.Stuart-Harris@act.gov.au

Ms Sarah Davenport
 School of Psychology
 Building 39
 The Australian National University
 Canberra ACT 0200
 Ph: (02) 6125 2147
 Email: Sarah.Davenport@anu.edu.au

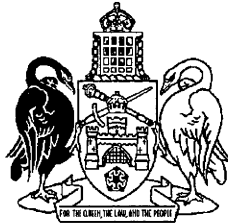
Professor Don Byrne
 School of Psychology
 Building 39
 The Australian National University
 Canberra ACT 0200
 Ph: (02) 6125 3974
 Email: Don.Byrne@anu.edu.au

Medico Moral, Human Research
 and Ethics Committee (MMHREC)
 Ms Raeleigh Mooney
 Secretariat of the MMHREC
 Ph: (02) 6201 6104

APPENDIX K

Patient Consent Form for Participants Attending The Canberra Hospital, The National Capital Private Hospital, and the John James Memorial Hospital

ACT Health and Community Care Consent Form



Australian Capital Territory

I, _____,

(name of participant)

of _____

(street)

(suburb/town)

(state & postcode)

have been asked to consent to my participation in a research project entitled:

Coping styles and the experience of chemotherapy

In relation to this project I have read the Patient Information Sheet and have been informed of the following points:

1. Approval has been given by the ACT Department of Health Ethics Committee and The Australian National University Human Ethics Committee.
2. The aim of the project is to investigate how people cope with chemotherapy and whether particular ways of coping are associated with better psychological and medical well-being.
3. The results obtained from the study may or may not be of direct benefit to my medical management.

4. The procedure will involve completing a questionnaire package which will ask me to consider the way in which I deal with situations as well as the general state of my emotional wellbeing. I will be asked to complete the package prior to, following the first 3-4 chemotherapy infusions, on completion and 6- and 12-months following chemotherapy treatment. In addition, information regarding my medical progress will be collected by the research team from my medical files.

5. My involvement in this project may be terminated if any of the following circumstances develop:

I am unable to complete the tasks involved in participation

My medical condition changes according to medical staff in the Department of Oncology, at The Canberra Hospital

6. Should I have any queries regarding participation, I am aware that I may contact:

A/Professor Robin Stuart-Harris

Department of Oncology

The Canberra Hospital

Yamba Drive

Garran ACT 2605

Ph: (02) 6244 2220

Fax: (02) 6244 4266

Email: Robin.Stuart-Harris@act.gov.au

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Ph: (02) 6125 2147

Fax: (02) 6125 0499

Email: Sarah.Davenport@anu.edu.au

Professor Don Byrne

School of Psychology

Building 39

The Australian National University

Canberra ACT 0200

Ph: (02) 6125 3974

Fax: (02) 6125 0499

Email: Don.Byrne@anu.edu.au

7. Should I have any problems or queries about the way in which the study was conducted, and I do not feel comfortable contacting the research staff, I am aware that I may contact:

The Secretary
ACT Department of Health Ethics Committee
North Building
Second Floor
London Circuit
Canberra City ACT 2601
Ph: (02) 6205 0846

The Human Ethics Officer
The Australian National University
Ph: 6125 7945
Human.Ethics.Officer@anu.edu.au

8. I can refuse to take part in this project or withdraw from it at any time without affecting my medical care in any way.

9. Participation in this project will not result in any extra medical and hospital costs to me. I will not receive any reimbursement for my involvement in the study.

10. I understand that the results of the research will be made accessible and that my involvement and my identity will not be revealed.

11. In giving my consent, I acknowledge that the research team directly involved in the study, may receive information from my medical records only as they relate to this project.

After considering all these points, I accept the invitation to participate in this project.

Signature (of Participant): _____ Date: _____

Signature (of Witness): _____ Date: _____

Signature (of Investigator): _____ Date: _____

APPENDIX L

Patient Consent Form for Participants Attending the Calvary Hospital

The Calvary Hospital Consent Form



I, _____,

(name of participant)

of _____

(street)

(suburb/town)

(state & postcode)

have been asked to consent to my participation in a research project entitled:

Coping styles and the experience of chemotherapy

In relation to this project I have read the Patient Information Sheet and have been informed of the following points:

Approval has been given by the Medico Moral, Human Research and Ethics Committee (MMHREC).

The aim of the project is to investigate how people cope with chemotherapy and whether particular ways of coping are associated with better psychological and physical well-being.

The results obtained from the study may or may not be of direct benefit to my medical management.

The procedure will involve completing a questionnaire package which will ask me to consider the way in which I deal with situations as well as the general state of my

emotional wellbeing. I will be asked to complete the package prior to, following the first 3-4 chemotherapy infusions, on completion of chemotherapy treatment, and one-year following chemotherapy treatment. In addition, information regarding my medical progress will be gained from my medical files by one of the research team but that this information will be recorded using my code number, not my name.

My involvement in this project may be terminated if any of the following circumstances develop:

I am unable to complete the tasks involved in participation or choose not to;
My medical condition as judged by medical staff in Calvary Health Care ACT changes in a way they believe is inconsistent with my further participation.

Should I have any queries regarding participation, I am aware that I may contact:

A/Professor Robin Stuart-Harris
Department of Oncology
The Canberra Hospital
Yamba Drive
Garran ACT 2605
Ph: (02) 6244 2220
Fax: (02) 6244 4266
Email: Robin.Stuart-Harris@act.gov.au

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The Australian National University
Canberra ACT 0200
Ph: (02) 6125 3974
Fax: (02) 6125 0499
Email: Don.Byrne@anu.edu.au

Should I have any problems or queries about the way in which the study was conducted, and I do not feel comfortable contacting the research staff, I am aware that I may contact Ms Raeleigh Mooney, secretariat of the MMHREC on (02) 6201 6104 and The Human Ethics Officer, The Australian National University, on (02) 6125 7945 or Human.Ethics.Officer@anu.edu.au.

I can refuse to take part in this project or withdraw from it at any time without affecting my medical care in any way.

Participation in this project will not result in any extra medical and hospital costs to me. I will not receive any reimbursement for my involvement in the study.

I understand that the results of the research will be made accessible and that my involvement and my identity will not be revealed.

In giving my consent, I acknowledge that the research team directly involved in the study will collect information from my medical records only as they relate to this project.

After considering all these points, I accept the invitation to participate in this project.

Signature (of Participant): _____ Date: _____

Signature (of Witness): _____ Date: _____

Signature (of Investigator): _____ Date: _____

APPENDIX M

Reminder Letter to Participants

Dear Participant,

Thank you for your continued support of our project, *Coping with Chemotherapy*.

Recently, you were sent a questionnaire which aimed to gain an update on your progress since completing chemotherapy. I did not receive your completed questionnaire and am very keen to see your progress at this point. If you have completed the questionnaire, I would appreciate it if you would return it to me. If for some reason you did not receive the questionnaire, I have enclosed another copy for you. I would greatly appreciate it if you would complete the questionnaire and return it to me in the reply paid envelope provided.

Please remember to complete all items in the booklet as best as you can and to write the date you completed it on the front cover. You will receive the final questionnaire package in another six months' time. We greatly appreciate your participation in this important study and appreciate the significant time and effort involved in participation.

If you have any questions regarding the questionnaire booklet or would like assistance with the completion of the questionnaire, please do not hesitate to contact me on the details below:

Yours sincerely,

Sarah Davenport

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